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The work of eight task force committees on mental retardation is considered in this report. Major findings and recommendations are summarized concerning the nature of mental retardation; present services for the mentally retarded; the role of volunteer organizations; prevention; case finding, diagnosis, and evaluation; public awareness; special education services; vocational training and employment; community care centers; residential facilities; and coordination and implementation of programs. Three appendixes list names of the Advisory Council on Mental Retardation, members of the problem study groups, and the editing committee and editorial staff. (BW)

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STATE OF TENNESSEE

DEPARTMENT OF MENTAL HEALTH

TENNESSEE PLANS FOR HER RETARDED CITIZENS

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DEPARTMENT OF MENTAL HEALTH

STATE OF TENNESSEE

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Nat T. Winston, M.D.	Commissioner

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STATE OF TENNESSEE
DEPARTMENT OF MENTAL HEALTH
CORDELL HULL BLDG. NASHVILLE, TENN. 37219

JANUARY 9, 1967

HONORABLE FRANK G. CLEMENT, GOVERNOR
STATE OF TENNESSEE
CAPITOL BUILDING
NASHVILLE, TENNESSEE

DEAR GOVERNOR CLEMENT:

IT IS WITH GREAT PERSONAL SATISFACTION THAT I TRANSMIT HEREWITH THE REPORT OF THE PLANNING COMMITTEES ON MENTAL RETARDATION IN TENNESSEE MADE POSSIBLE THROUGH FEDERAL FUNDS AND APPOINTED BY YOU. THIS EXCELLENT REPORT REPRESENTS THOUSANDS OF HOURS OF DEDICATED WORK ON THE PART OF THE MOST KNOWLEDGEABLE PROFESSIONAL AND LAY PEOPLE IN THE STATE OF TENNESSEE. IT IS HOPED THAT THIS PLAN WILL SERVE AS A BLUEPRINT FOR THE FUTURE PROGRAM FOR THE MENTALLY RETARDED IN TENNESSEE.

KNOWING OF YOUR KEEN INTEREST IN THIS FIELD AND YOUR MORE THAN GENEROUS SUPPORT IN THE PAST AND WITH THE HELP OF MANY PEOPLE ACROSS THE STATE, TENNESSEE WILL MOVE FORWARD AND HOPEFULLY SET THE PACE FOR THE REST OF THE NATION.

YOURS SINCERELY,

NAT T. WINSTON, JR., M.D.
COMMISSIONER

NTW/EA

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FOREWORD

FOREWORD

This report represents the result of studies by persons in the State of Tennessee interested in the mentally retarded. Nine committees of laymen, professionals and other citizens, appointed by the Tennessee Department of Mental Health, have been working diligently on this project since January of 1965. The reports of these committees are intended to result in a plan for beginning a comprehensive action to combat mental retardation as required by United States Public Law 88-156. The full report of each committee is available from the Tennessee Department of Mental Health. This report contains the consolidation of the work of eight task force committees. They are:

Committee on Coordination and Implementation of Programming for the Mentally Retarded

Committee on Case Finding

Committee on Residential Facilities

Committee on Special Education Service

Committee on Community Care Centers

Committee on Public Awareness

Committee on Employment Opportunities for the Mentally Retarded

Committee on Volunteer Organizations

A complete list of the committee members and other personnel involved in these studies is listed in Appendix A to this report.

Each committee functioned separately and independently from the other committees with the Department of Mental Health furnishing some liason between committees and such coordination as was felt to be helpful without interferring with the independence of each study group. Once each study group had made its report the reports were condensed and edited to eliminate over-lapping and to provide continuity and consistency of content by a special editing committee of the Advisory Council on Mental Retardation.

It is recognized that other phases of the problems of retardation could have been treated separately by special committees. Research, prevention, and the retarded and the law are three phases which could well have been topics for special committee consideration. These topics are touched on by the reports of several of the committees. Some of the reasons for leaving out a special project on the retarded and the law include the fact that the Law Revision Commission is presently engaged in making a study of the criminal laws of the State of Tennessee which will touch upon aspects of the problem. Tennessee has recently changed its law regarding admissions of retardates as well as mentally ill persons to State institutions. A special research project is underway at George Washington University for the purpose of designing a uniform approach that all the states can take in this regard. The Legislative Council committee has had two studies touching upon this subject and various State departments have completed or are in the process of revising many of their rules and regulations that touch the retarded.

As noted in several of the chapters prevention is the most vital link in the chain of services to the retardate. In fact, the thrust of this entire report is that the programs here proposed are calculated to prevent retardation where that is possible and where that is not possible, to prevent the disastrous consequences of retardation where, by use of an enlightened and dynamic program, these consequences can be avoided. For convenience to the reader especially interested in both these types of prevention, a short chapter is included that sets forth the high-lights of the committee findings and recommendations directly bearing upon prevention.

No inventory of the various research projects currently being undertaken in the State was made. In a sense, every facility dealing with the retarded, every civic group or state program for the retarded is to some degree engaged in research and experimentation. Our private universities and hospitals as well as our state institutions are involved in research projects and one of the main reasons that the committee on Community Care Centers recommended that the regional facilities be located within the shadow of universities and hospitals was because this is calculated to get these universities and hospitals more involved in retardation research. Furthermore, one of the considerations for recommending a Special Assistant for the Governor in the chapter on Coordination and Implementation and recommending closer cooperation between the various professions and disciplines was that it is recognized that our research facilities need to be made more aware of the opportunities and needs for expanded research, they need to be more closely coordinated and there needs to be a greater flow of information between them.

In short, it is recognized that this report is neither all inclusive nor exhaustive. It is a plan for a beginning. We are late. There is much else that could be said but even more than must be done.

Floyd Dennis, Project Editor
Shelbyville, Tennessee

SUMMARY OF MAJOR FINDINGS

1. Tennesseans generally are unable to distinguish between mental retardation and mental illness.

2. Tennesseans are not only unaware of the nature of retardates but have many false ideas and misconceptions that have served to slow progress in the entire field of retardation.

3. State programs have been limited mainly to residential care in state institutions and aid to a limited number of special education classes and sheltered workshops.

4. There is little coordination between departments or between agencies of the same department in finding and meeting the needs of retarded Tennesseans although they are estimated to compromise 3% of the population and problems of retardation directly affects an estimated 10% or more of our population.

5. Nearly all of Tennessee schools and colleges offer insufficient or no courses or materials relating to mental retardation. This is true even of schools teaching professionals who will deal with retardates, e. g., doctors, lawyers, teachers, police and social workers.

6. Most retardates do not belong in large central institutions. Moderate and even severely retarded profit most by being kept at home or in the home community if adequate services to retardates and their families are available.

7. Failure to spend money to evaluate, train and habilitate retardates in their community is false economy since more than three-fourths can become self-supporting or productive members of society.

8. The problems of retardation cut across traditional lines of action in both our public and private sectors and, therefore, call for special instruments of coordination and communication if the problems are to be recognized and solved.

9. Early identification and evaluation is essential to effective programs to prevent retardation or to effectively aid those cases that are not preventable.

10. While there is a severe shortage of technically qualified people to do all that needs doing, and while there is much we don't know about retardation, we have sufficient knowledge and personnel to make tremendous progress if Tennessee makes a resolute committment to a comprehensive program for its mentally retarded citizens.

11. The mentally retarded are citizens and as such are, by the U. S. Constitution entitled to "the equal protection of the laws." The spirit of this philosophy urges that retardates are entitled to be educated, trained and equipped for life according to their capabilities just as other citizens are educated, trained and equipped for life according to their capabilities.

SUMMARY OF MAJOR RECOMMENDATIONS

		See Chap.
1.	The governor should appoint a Special Assistant on Mental Retardation. He would have an executive assistant and clerical help.	10 8
2.	There should be an Interagency Committee composed of a high-level representative from each department or agency with the special assistant serving as chairman.	10
3.	The governor should expand the Advisory Council on Mental Retardation to a total of fifty (50) lay and professional leaders. The Special Assistant would serve as executive secretary.	10
4.	Six (6) regional community care centers should be established at Memphis, Jackson, Nashville, Chattanooga, Knoxville, and Johnson City. Each center would provide comprehensive diagnostic services, consultants for smaller centers in the region and a full array of services for the retarded. The Centers would be located, insofar as practical, on the campus or in close proximity to a university and would cooperate closely with the university.	8
5.	Community care centers should be established in Oak Ridge, Kingsport and Bristol, and each should provide a full array of service exclusive of diagnosis and services for the surrounding area.	8
6.	Smaller community care centers should be established in the remaining approximately 25 communities having a population over 10,000. The services would vary somewhat with the population, residential facilities being omitted in all but the largest communities.	8
7.	Still smaller community care centers should be established in the remaining 40 or 50 counties or communities located in sparsely settled rural areas. Services would vary extensively with population, but each would have SMR and EMR classes and perhaps a combination of day-care, sheltered workshop and vocational training service.	8
8.	The State should assign a licensed architect to study the facilities needed, to prepare typical plans and to assist each community in selecting a site and in planning its community care facilities.	8
9.	The community care centers should be administered by a local non-profit corporation organized for the purpose.	8
10.	Institutional facilities should not be set apart from communities by fences or other barriers.	9

11. The central institutions should replace the ward system of living facilities with cottage type arrangements. 9

12. Locked facilities should be unlocked and training and activity programs substituted for custodial and unprogrammed care. 9

13. A research consultant position should be established at each central institution. 9

14. A professional category of "training specialists" should be established and included in the organizational tables of the satellite or regional centers. 9

15. Full-time or part-time program consultants should be continuously employed by the Department of Mental Health to insure that all future facilities and services are well-planned. Too often in the past program decisions have been relegated to architects employed to design the facility. 9

16. Institutions should be operated under a flexible admission and release policy with an increased emphasis on out-patient services. 9

17. The position of Director of Standards for Mentally Retarded Care Centers should be established to set licensing standards for all institutions providing care for retardates and to set rates which would permit these licensed institutions to maintain the required standards. 9

18. Coordination and cooperation of volunteer organizations and governmental agencies is needed at all levels. The state must offer leadership to encourage this needed coordination and cooperation.

19. Institutions must make a place for volunteers. Both the administrative and line personnel must welcome volunteer assistants, clearly develop and describe jobs assigned to volunteers. Every institution should have a volunteer representative at staff or faculty meetings. 3

20. More aggressive case work service should be made available to the families of applicants for institutional care. 2

21. Professions involved with day care work should be made aware of the value and need for day care facilities for the retarded. 2

22. A directory of services for the retarded in Tennessee should be compiled and published immediately and kept up to date. Schools, colleges and universities (both public and private) should provide mental retardation subject matter in professional education and should offer expert assistance in special programs. 6

23. There should be an intensive effort to promote the use of materials on mental retardation in regular publications of professional organizations, volunteer organizations, religious organizations, and state departments and agencies. 3

24. Well-baby clinics and other centers serving large numbers of infants and young children should try to develop screening procedures operated by volunteers to facilitate early recognition of retardates. 3

25. Volunteer groups should be encouraged to offer home-maker services for the families with retarded children, to relieve the harried mother, and to teach more efficient housekeeping methods and child-rearing practices. 3

26. Physicians, public health nurses, social workers and other professionals need to be kept acutely aware of the opportunity for identification of the retarded signaled by such things as infection, RH factor incompatibility, chromosomal disorders occurring in the history of patients or their relatives. 4

27. The Department of Public Health should assume the responsibility for seeing that no mother shall be denied needed pre-natal care and training. The Department of Public Welfare and other welfare agencies should be actively involved in this prenatal program. 4

28. Mandatory minimum standards and procedures need to be established by law to assure that all delivery facilities are able to cope with birth emergencies that could produce retardation. 4

29. Public and professional information programs reminding professionals and the general public that avoiding infectitious diseases such as rubella , ruebolla and others can be an effective means for preventing some forms of retardation. Parents of mongoloids should be given genetic and birth control counseling. 4

30. The state should legally require that all infants be tested for PKU. 4

31. The educational and training objectives of special education should be reviewed and directed toward development of (a) occupational adequacy, (b) social competence consistent with the work level a retardate will assume, and (c) personal adequacy. 7

32. Legislation should be enacted to provide pre-school or preparatory classes for retardates. 7

33. Area diagnostic centers should be developed or existing community mental health centers should be expanded to service families of the retarded. This is important because at present the family of the disadvantaged individual is usually the forgotten and neglected problem. 7

34. The training centers now being established across the state should be developed into Comprehensive Work Evaluation and Training Centers incorporating a well-planned job placement and follow-up program. These centers should expand their programs to handle also the more severely retarded. 7

35. Once a person is served by the Division of Vocational Rehabilitation, his case should not be closed as "rehabilitated" until at least six months in employment have passed rather than the present two months. 7

36. The state should provide assistance in developing more sheltered workshops in connection with the work training centers. 7

37. Every school system should be required to have at least one (1) class for severely mentally retarded, adequately staffed, for every fifteen (15) retardates. 6

38. The educational evaluation of mentally retarded individuals should be based upon a more comprehensive diagnosis which would be used as a basis for placement in classes with better planned curricula. In some SMR classes the "curriculum" is little more than baby-sitting and in some EMR classes the curriculum is so watered down as to be of little value. 6

39. Students in special education programs should have a well-rounded school program which would stress, however, manual skills rather than academic training. Retardates need more physical education programs and pre-vocational and vocational classes. 6

40. There should be a written agreement among the state agencies which will be supplying the various services needed by the special education classes guaranteeing a "dovetailing" of services. 6

41. A mandatory class attendance code with legal enforcement for all retardates eligible for school attendance should be more stringently enforced. 6

42. A records system to follow retardates from identification through job placement is recommended. 6

43. The State Department of Education or university departments of education should establish a mental retardation instructional materials center to insure efficient classroom instruction of retarded children. 6

44. Teachers for retardates should have to meet special requirements for qualification . 6

45. Nurses, policemen, probation officers, and others working directly with retardates should have supervised experience included in their training programs. 6

46. Every child, regardless of the parent's financial status, should be screened soon after birth for metabolic disorders, e. g., phenyketonuria, galactosemia, and maple syrup urine disease. 5

47. Improved communications between the State Departments of Public Health, local health departments, private practioneers, medical schools, the Department of Education, the Public Welfare Department and the Mental Health Department should be effected. 5

48. Emphasis should be placed on training social and welfare workers to recognize early symptoms of mental retardation in young children. 5

49. Continuous health supervision should be exercised over children reported in the "High Risk" category. 5

50. Kindergarten should be made a part of the public school system with attendance compulsory at age six and desirable at age five. Kindergartens, which have as their main purpose the evaluation of the child's readiness for school, can play a major role in case finding. 5

51. Every child entering the first grade should be given readiness tests and those adjudged "not ready" referred to complete evaluation. 5

52. Group IQ tests, both verbal and non-verbal, should be administered to all children by the fourth grade. 5

53. All children should be referred to the pupil personnel services for further study upon their failure to complete satisfactorily any grade in school. 5

54. There should be an immediate referral of the name of all "drop-outs" to the Division of Vocational Rehabilitation in order that evaluation, guidance, and training may be immediately instituted. 5

55. Highly trained professional persons should be employed to devise examinations for use in case finding which can be administered by non-professional persons under adequate supervision. 5

56. An expanded staff in the Division of Vocational Rehabilitation is necessary to serve adequately the retarded adults throughout the state. 5

57. Additional funds must be allocated to the institutions sponsoring training for work in the area of mental retardation. 5

58. Tennessee should establish the University Affiliated Training Centers for "physicians and other specialized personnel needed in the field of mental retardation " which are 5

provided for in Public Law 88-164.

THE NATURE OF MENTAL RETARDATION

THE NATURE OF MENTAL RETARDATION

I. MENTAL RETARDATION DEFINED

Feeblemindness, imbecility, moronity and amentia are a few of the words which have been used in the past as names for conditions now included in the broad term "mental retardation." "Mental retardation is not a disease, but rather a symptom of a disease, of an injury, of some obscure failure of development, even of inadequate opportunity to learn.... It can be so severe that the afflicted person never leaves protective care, or so mild that it is detected only under stress or through special tests." A mentally retarded person is one who at birth or in his growth years has or develops a handicap in his thinking ability that robs him of the power to function or act like a person of his age that has ordinary thinking ability. That is, it refers to below-average intelligence which starts at birth or during a child's growth period and is associated with the failure to think and act as effectively as the average person of the same age.

The American Association of Mental Deficiency has defined mental retardation as: "sub-average general intellectual functioning which originates during the development period and is associated with an impairment in adaptive behavior." The President's panel on mental retardation stated it slightly differently by referring to the mentally retarded as "children and adults who, as a result of inadequately developed intelligence, are significantly impaired in their ability to learn and to adopt to the demands of society."

II. MENTAL RETARDATION DISTINGUISHED FROM MENTAL ILLNESS

To a large extent, the public's misunderstanding of mental retardation is the result of confusing it with mental illness. While the same individual may manifest both problems (the mentally retarded may also become emotionally disturbed), in most instances the problems are separate. Briefly, mental illness is a disorder of the personality or the emotions while mental retardation is a condition characterized by subnormal intellectual development. Mental retardation can be caused by any condition which interferes with a person's intellectual development before, during, or after birth. There is resulting brain dysfunction which will manifest itself during the newborn or early childhood period and for which at present there is no treatment to lift the person to normal intelligence. The mentally ill person may be born with full mental capacities but later becomes emotionally disturbed. Worry, frustration, shock, and other pressures of the present-day world can cause one of the several types of mental illness. Early diagnosis and proper treatment can restore the individuals to normality.

III. THE CAUSES OF MENTAL RETARDATION

All agree that the key to prevention and correction of mental retardation is an understanding of its causes. This is a difficult assignment, however, as the causes are incredibly complex as evidenced by the fact that while nearly two hundred (200) causes have been identified, these account for only 15% to 25% of the known cases. Some of the better known causes are:

(1) Pregnancy complications - bleeding, toxemia poisoning, hypoxia.
(2) Prematurity - 70% of infants weighing less than 3.3 pounds have physical and mental disorders.
(3) Conditions during labor and delivery - irregular positions of child, pressures on baby's head during delivery, improper use of forceps.
(4) Blood problems - RH blood factor incompatibility.
(5) Medicine and drug problems - excessive amounts of vitamin K, sulfa compounds, phenobarbital.
(6) Infections - tuberculosis, measles, syphillis.
(7) Metabolic disorders of mother - diabetes, pupura.
(8) Chromosomal disorders - mongolism, mosaicism.
(9) Inborn metabolic errors - PKU, cretinism.

Because a high proportion of retarded children are from the disadvantaged classes of society, it is reasonable to conclude that adverse social, economic and cultural factors play a major causative role in mental retardation. Children born into these groups suffer from inadequate prenatal, natal and postnatal medical care and also from an impoverished educational environment. Therefore, any meaningful attack on mental retardation must strike at the root problem of poverty which nourishes many of the above specific causes.

One should not, however, conclude that mental retardation is confined to the lower socio-economic classes. President Kennedy acknowledged publicly that one of his sisters has been an institutionalized retardate for many years, and Vice-President Humphrey has a retarded grand-daughter. Entertainer Count Basie, baseball player Del Crandell, and the former Governor of Kentucky, Bert Combs, all are parents of retarded children. These are only a few examples of retardation affecting people who are well known in our society.

IV. THE FOUR LEVELS OF RETARDATION

While the definitions of mental retardation found in Section I above give one a broad concept of the problem, obviously there are varying degrees of retardation. The following discussion taken from the book, National Action to Combat Mental Retardation, are most illuminating on this subject:

> "Because mental retardation is a relative concept depending on the prevailing educational and cultural standards, there is no completely satisfactory measure for mental retar-

dation. Current scientific usage favors groupings based on the intelligence quotient (IQ) and adaptive behavior of the person. Four groupings are commonly used - profound, severe, moderate, and mild. They range from the situation where evidence of human adaptation is almost totally absent to that where the degree of impairment is minimal and the difference from normality almost indistinct.

"As designated under the four categories based on intelligence quotient, those individuals who are considered profoundly retarded (IQ usually below 20) and those designated as severely retarded (IQ from about 20 to 35) need constant care or supervision throughout their lives if they are to survive. In these groups are the anencephalies, human beings without cerebral cortexes, and the more seriously impaired Mongoloids....It is estimated that one child out of every one thousand born ....falls in these two groups.

"The moderately retarded persons (IQ usually 35 to 50).... are capable of developing self-protection skills and mastering limited skills for semi-productive effort so they can contribute partially to their self-support if given an adequately protected environment. An estimated three children per one thousand births will become moderately retarded, unlikely to progress beyond a mental age of seven (7) years even in adulthood.

"Finally, the mildly retarded (IQ usually 50 to 70 but sometimes including those of slightly higher IQ) comprising the largest groups.... are usually not distinguishable from normal individuals until school age when they are often identified by an inability to learn general school subjects. Without special attention, they often become the problem members of our society, capable only of a marginal productive role. They are the workers who are the most frequently displaced by the economic adjustments in our competitive society. However, given timely supervision, guidance, and training early enough in life, many will be capable of complete assimilation into our society.... It is estimated that about twenty-six (26) out of every one thousand children born will be mildly retarded at some time in their lives."

The following chart by the President's Panel on Mental Retardation gives a capsule summary of the developmental characteristics potential for training and education and social and vocational adequacy of the four classes of retardates.

*Array of Direct Services for the Retarded**

Life stage	Components of special need
	Physical & mental health - Shelter nurture protection - Intellectual development - Social development - Recreation - Work - Economic security
Infant	Specialized medical follow-up Residential nursery Special diets, drugs or surgery Sensory stimulation Child welfare services Home training
Toddler	Home nursing Environmental enrichment Correction of physical defects Foster care Nursery school Physical therapy Trained baby sitter
Child	Classes for slow learners Playground programs Psychiatric care Homemaker service Special classes—educable Special classes—trainable Dental care Day care Religious education Scouting Swimming
Youth	Short stay home Work-school programs Day camps Residential camps Boarding school Speech training "Disabled child's" benefits Psychotherapy Occupational training Youth groups Social clubs Health insurance
Young adult	Half-way house Vocational counseling—Personal adjustment training Selective job placement Facilities for retarded in conflict Guardianship of person Marriage counseling Sheltered employment Total disability assistance Long-term residential care Sheltered workshops
Adult	Bowling Guardianship of property Life annuity or trust Group homes Evening school Social supervision
Older adult	Evening recreation Boarding homes Medical attention to chronic conditions Old age assistance OASI benefits

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*Not included are diagnostic and evaluation services, or services to the family; the array is set forth in an irregular pattern in order to represent the overlapping of areas of need and the interdigitation of services. Duration of services along the life span has not been indicated here.

In Tennessee and elsewhere the retarded often are divided into three levels of retardation. Especially in education circles the retarded have been referred to as follows:

(1) EMR - the educable mentally retarded. This generally designates the same group as are described in the above chart as mild and includes those with an IQ of about 50 and above.
(2) SMR - the severely mentally retarded. This would include the moderate and a portion of those categorized as severe in the above table. The relative intelligence quotients of this group range from about 30 to about 50. This group is often called the TMR or Trainable Mentally Retarded.
(3) Custodial or dependent. This refers to those categorized as profound and some of the group categorized as severe. This is the group for which little training is indicated or recommended at the present time.

V. ARRAY OF DIRECT SERVICES FOR THE RETARDED

You can see from the levels chart that a wide array of services is needed for the retarded because of age and level differences. The next chart shows many of the services a retardate needs as he grows from an infant to an older adult.

These and other services are discussed in this report. The chart makes a good check-list for finding inadequacy of service available in a community and areas where individuals or organizations can be of help.

VI. THE SCOPE OF THE PROBLEM

To appreciate the scope of the problems of mental retardation, one need only to consider the following statistics and comparisons. An estimated 3% of the population or 5.7 million children and adults in the United States are afflicted with the varying degrees of mental retardation discussed in Section IV. Using the generally accepted 3% prevalance rate, Tennessee had approximately 114,000 retardates in 1964 and will have 120,000 by 1970. Furthermore, it is possible that the 3% estimate is too low for Tennessee in view of the fact that during World War II, nearly 10% of the persons examined in the Southeast by the Selective Service were rejected on grounds of "mental deficiency."

MENTAL RETARDATION, AS A DISABILITY, AFFLICTS TWICE AS MANY INDIVIDUALS AS BLINDNESS, POLIO, CEREBRAL PALSY, AND RHEUMATIC HEART DISEASE, COMBINED. IT DISABLES TEN TIMES AS MANY AS DIABETES, TWENTY TIMES AS MANY AS TUBERCULOSIS, TWENTY-FIVE TIMES AS MANY AS MUSCULAR DYSTROPHY AND SIX HUNDRED TIMES AS MANY AS

INFANTILE PARALYSIS. In fact, only four significant disabling conditions - mental illness, cardiac disease, arthritis, and cancer - have a higher prevalence but they tend to come late in life while mental retardation comes early and continues throughout life.

While only 4% of all retardates are cared for in public institutions, states and communities spent an estimated $300 million a year for their care. An estimated additional $250 million from public funds is spent annually for special education, welfare, rehabilitation, and other benefits and services for retardates outside of public institutions. Furthermore, the federal government in 1962 obligated an estimated $164 million for the mentally retarded, nearly double the amount of 1957.

But the financial burdens of retardation are only minor when compared to the emotional strains imposed upon the parents as they first must accept the fact and then attempt to train and school the child for as full a life as possible. This is the major impact of retardation on society.

WAITING LISTS AT RESIDENTIAL INSTITUTIONS

AND

PRESENT SERVICES FOR THE MENTALLY RETARDED

This chapter is not the product of a Task Force Committee but was prepared under the direction of the editing committee from date in the "1965-'66 Tennessee State Plan for the Construction of Facilities for the Mentally Retarded" of the Department of Mental Health; from the report of the study of waiting lists done under a supplemental federal grant and from data developed by the editing committee. It is inserted by authority granted by the ADVISORY COUNCIL ON MENTAL RETARDATION.

Present Services for the Mentally Retarded

There are no thoroughly reliable figures on the number of mentally retarded now being served in Tennessee. Even more important there are no reliable measures of the quality of existing services. The most recent figures available are those shown in the report of the Department of Mental Health "1965-66 Tennessee State Plan for the Construction of Facilities for the Mentally Retarded." Even these rather voluminous tabulations by types of services and by counties must be used with caution because they are likely to contain the errors normally inherent in data obtained from surveys conducted by mail. Replies were not received from some of the organizations canvassed. More significant without a careful field check there was no way to eliminate overlap between services received by the same individual on a part-time basis from several organizations or to include the many part-time or seasonal services provided in some areas by member units of the Tennessee Association for Retarded Children and Adults or by local civic groups working with the member units.

Major services available to the mentally retarded of Tennessee are summarized in the following sections. The figures on the number being served are only approximate. This lack of reliable figures serves to emphasize the recommendation made elsewhere in this report that the Tennessee Association for Retarded Children and Adults should take the leadership in preparing and maintaining, in cooperation with appropriate state agencies, a current roster of services for the retarded in each community. (See "Volunteer Organization Services For the Retarded", Chapter 3).

The following summary of continuing services for the retarded, exclusive of residential care, is particularly interesting in that it shows the wide discrepancy between the number served per 100,000 population in the three grand divisions of the state. Even more significant, available figures indicate that in Hamilton County the number being served is about 650 per 100,000. This Hamilton County figure is more than twice the state average and almost three times the average for West Tennessee. These figures say, in effect, that the number served throughout the state would need to be doubled to reach present standards in the more progressive counties.

Summary of Continuing Services - Exclusive of Residential Care

Area	Population 1960 Census	Retarded Served Total	Per 100,000
Hamilton County	237,905	1,548	650
Anderson County	60,032	303	505
Knox County	250,523	1,206	481
Montgomery County	55,645	267	480
Blount County	57,525	271	470
Washington County	64,832	278	429

Cont.

East Tennessee	1,047,222	5,605	535
Middle Tennessee	1,076,809	3,232	300
West Tennessee	1,083,058	2,505	232
Tennessee	3,567,089	11,342	318

Summary of All Services

	Number being served
Continuing services	
Residential care	2,400+
Special classes for EMR	9,095
Special classes for SMR	1,197
Pre-school classes	100+
Day care	100+
Vocational training	750+
Sheltered workshops	150+
Total	13,792
Intermittent services	
Comprehensive diagnosis	249
IQ testing	3,500+
Job evaluations	400+
Recreation	
Residential camps	180
Playgrounds	?
Swimming	?
Bowling	?
Day camps	?

I. Residential Services

The State of Tennessee first exhibited concern for the mentally retarded in 1919 when the legislature appropriated funds for the purchase of land and construction of buildings to house the "feeble-minded." The Tennessee Home for the Feeble-Minded opened its doors in September, 1923. Operation of the home was an added responsibility of the Department of Institutions. Since operation of the state prisons was the major responsibility of this department, the atmosphere was that of a prison rather than a "home."

The 1953 legislature, upon the recommendation of Governor Clement, created the Department of Mental Health, changed the name to Clover Bottom Home, and transferred the home and the state institutions for the mentally ill to the new department. Facilities were expanded over the years, particularly with construction in 1958 of an educational building and a research unit. About 1,400 patients are now housed at Clover Bottom.

The Greene Valley Hospital and School opened in December 1960 with seven cottages (each designed to house 44 patients), a food services building, and a laundry. These cottages with eight rooms designed for four patients each and six rooms designed for two patients each, were a radical departure from the wards at Clover Bottom with fifty or more patients. In addition, each cottage was constructed with a nursing station, modern bathroom facilities, an active day room, a quiet day room, a serving room, and dining room. The therapeutic philosophy also departed radically from past practice in Tennessee. The doors remained unlocked and the patients were free to go in or out of the buildings at any time of the day. The patients were also given freedom of the grounds except for certain areas marked "off limits." And there were no restrictive fences around the grounds. Construction of additional cottages and various service buildings continues toward the planned size of 1500 beds. About 900 patients are now housed.

Construction was started in 1966 on a third state institution for the retarded at Arlington, about 20 miles from Memphis. It will also have an ultimate capacity of about 1500 beds, making a total of about 4,500 beds in the three state institutions.

Residential services are also provided by a number of relatively small private institutions of which the King's Daughters Hospital at Columbia is the largest and best known. About 46 are in residence. The Martha's Vineyard School at Springfield, the Louisa School at Murfreesboro, Happy Acres at Memphis, Happy Haven Farm at Shelbyville, and similar small residential facilities bring the total to an estimated 100.

II. Special Education Services

Equally rapid progress has been made in recent years in providing special education and training for the mentally retarded of Tennessee. The Shriners began a program for crippled children of the South in 1919 and constructed a number of hospitals but did not make provision for education of these children. Upon release from a hospital, these children were so far behind educationally that it was difficult for them to progress in the regular school classes. Rotary International began to provide special education in the hospitals but the depression of the early 1930s stopped this. In the latter part of the depression, the American Legion joined with Rotary International in continuing this education. The Department of Public Health began providing teachers in these hospitals for crippled children in 1945. This was the first of the state's special education services. The Department of Education started a sight conservation program in 1947 and a program for speech and hearing in 1949. Special classes for the educably mentally retarded began in 1951. The number of such classes has increased over the years until there were 609 classes in 75 of Tennessee's 95 counties with a total enrollment of 9,095 children during the 1964-65 school year.

Formation in September 1950 of what is now the National Association for Retarded Children and formation in July 1952 of what is now the Tennessee Association for Retarded Children and Adults caused a rapid increase in concern for other special programs for retarded children. These parent groups began to develop in various parts of Tennessee special classes for the trainable retarded -- those who could not be "educated" in the usual sense but could be trained to be more useful and less of a burden at home and in the community. Organized and paid for by the parents, these classes were held wherever space could be found and were taught by almost anyone who could be employed.

Pressure from these parents and from TARCA mounted rapidly for establishment in the public school of special classes for the severely mentally retarded. As a result, Dr. Quill Cope, Commissioner of Education, called a series of meetings starting in April 1954 to discuss what action should be taken. These meetings culminated in adoption by the 1955 legislature of a bill to provide for the training of severely retarded children in the public schools with the State Department of Education paying about 60% of the cost. The number of such classes has increased over the years until there were 87 classes in 36 of Tennessee's 95 counties with a total enrollment of 1,197 children during the 1964-65 school year.

The need for pre-school classes to prepare children for entrance into the special classes has been recognized but little progress has been made. A class in Knoxville is operated by the Sertoma Club, classes in Memphis by the Duration Club, and a class in Chattanooga by United Cerebral Palsy. Total enrollment is about 50.

III. Workshop Services

Vocational training for the retarded is receiving increasing recognition as an essential program if many of those educated and trained in the EMR(educable mentally retarded) classes are to obtain and retain remunerative jobs in the community. Some of the graduates of the SMR (severely mentally retarded) classes may be able to profit from vocational training, and although most will not be able to operate in a competitive environment many can operate in a sheltered environment. Sheltered workshops are needed to provide this type of employment. Both types of programs are operating to some extent in Tennessee. In many instances the two are so interrelated that it is difficult to obtain reliable figures on the number served by each.

Orange Grove School at Chattanooga started a training center and sheltered workshop many years ago that now serves 100 to 127 depending upon the workload and other factors. Goodwill Industries, first in Memphis and then in Nashville and Chattanooga, provide training as well as sheltered employment for the handicapped, but the number of retarded has had to be limited to some extent in order to maintain balanced operations.

Memphis Goodwill Industries, a volunteer organization, serves handicapped persons who have limitations which pose problems in securing employment in private industry or business. Goodwill Industries provides employment, training and rehabilitation to a wide range of handicapped persons through the collection, processing and merchandising of clothing and household discards.

A special program has been inaugurated for the mentally retarded. For these persons Goodwill Industries provides a Vocational Evaluation and Training Program. Graduates move directly to Goodwill Industries' placement service, or they may be diverted to a long range program for training and development of acceptable work habits and personality characteristics (described in Chapter II). Those who successfully complete this training are then transferred to Goodwill Industries' placement service. A full time placement officer is employed to selectively place the retarded in outside industry.

In Knoxville, the Van Gilder Occupational Training Center was formed in 1959 within the school system to provide the less severely retarded with a combination of manual and educational training. Present enrollment is about 120 with each student scheduled to remain three years. The Dempster Memorial Workshop, also in Knoxville, operates as a training center for about 15 less severely retarded but is now in the process of expanding to be able to include the more severely retarded and to function partially as a sheltered workshop. In Memphis, the Sheltered Occupational Shop serves a small number that varies considerably with the workload.

The Volunteer State Vocational Training Centers, created by the Tennessee Association for Retarded Children and Adults under a Federal grant made available in 1962, was the first broad-scale effort to provide vocational training for the retarded of Tennessee, particularly in non-metropolitan areas. The first center was opened July 1, 1962, with additional centers added until the planned total of ten was reached before the program was transferred to the Division of Vocational Rehabilitation on August 1, 1965, by act of the 1965 legislature. Up to that time, the ten centers provided training for a total of 705 handicapped persons. Since that time, additional centers have been opened and the number of clients increased.

From the available statistics it is estimated that about 750 retarded persons are now receiving vocational training each year and another 150 are working in sheltered workshops. Such facilities operate in a total of 13 of Tennessee's 95 counties.

IV. Day Care Services

Day care services for the retarded are almost totally lacking in Tennessee. Day care is not just a babysitting service but includes specialized training for those who are so severely retarded that they cannot profit from the SMR classes or from a sheltered workshop. By providing specialized training, day care can develop many basic self-help skills such as dressing, eating, toilet habits, and personal grooming, thereby making the retarded more acceptable in and outside the home.

Only sketchy information is available on the number of retarded served in day care centers. The day care center on Murphy Road, Nashville, serves about 30. The United Cerebral Palsy centers in the major cities provide day care for a number who suffer from retardation as well as cerebral palsy. It is doubtful that day care services are provided for more than about 100 mentally retarded throughout Tennessee.

V. Diagnosis

Of all services provided the retarded, none is more important than an adequate and thorough diagnosis. It is the starting point in planning both the short-term and the long-term programs to meet the particular needs of each retarded person. And yet diagnosis is the weakest link in the chain of services for the retarded of Tennessee. It is almost a missing link in most parts of the state. Only the Child Development Clinic in Memphis now performs a comprehensive diagnosis. Last year 249 comprehensive evaluations were performed.

Less complete diagnosis, usually limited to little more than IQ tests, were performed by many agencies and private psychologists. The Department of Education reports 2,611 psycho-educational evaluations during 1964-65. Vanderbilt University performed some 800 tests , and the Mental Health Centers in the major cities performed about 100. In addition, the Volunteer Vocational Training Centers provided job evaluations for their clients.

VI. Other Services

A variety of other services for the retarded are provided by member units of the Tennessee Association for Retarded Children and Adults, often with the assistance of local civic organizations. Recreation is the most common, but parent counseling and special Sunday School classes are provided in some communities. The best known of the recreation activities are the two-week residential summer camps for about 130 children operated by the Chattanooga ARC and the similar camp for about 50 operated by the Carter County ARC. Other recreational activities include swimming, bowling, teenage parties and special playgrounds. No reliable figures are available on the total number served by these activities.

VII. Waiting Lists at Residential Institutions

In the midst of carrying out the detailed studies on the part of the citizens' committees, the Department of Mental Health was suddenly faced with the problem of doing something about the waiting lists at the institutions for the retarded, particularly at Clover Bottom Hospital and School, Donelson, which serves the highly-populated middle and west Tennessee areas which include the cities of Memphis and Nashville.

As an emergency measure, the Department of Mental Health asked for a supplemental grant to study those persons on the waiting list from Davidson and its surrounding rural counties of Cheatam, Robertson, Rutherford, Wilson, Sumner, and Williamson.

Mr. Ralph Horan was employed to make the study and was housed in the office of the Executive Secretary of the Davidson County Welfare Commission. At the time of Mr. Horan's employment, there were 243 persons on the waiting list from Davidson County alone. Thirty-two were also awaiting admission from the surrounding rural counties.

Because of the heavy duties encumbent upon any welfare agency, the waiting list from the Davidson County area had not been kept up to date, but as far as possible, every person whose name appeared on the list was located and the applicant and his family were interviewed.

Some parents had placed their children on the waiting list, looking ahead to the time when they would no longer be able to care for their children; others had placed their children on the waiting list because their family physician had recommended institutionalization even though the parent had not really wanted to give up the child. A few of the registrants had died but relatives had failed to notify the Davidson County Welfare Commission of the individual's death. A number had moved out of the State.

In some homes, emergency situations which seemed to call for immediate institutionalization were found. In these instances, the Davidson County Welfare Commission and the Social Service Department ot Clover Bottom Hospital and School were both notified. As a result, the "emergency" cases were taken into Clover Bottom as early as possible.

The majority visited were multi-problem families. They lived in the lower socio-economic sections of town, had deteriorated homes and were often unemployed or underemployed. They appeared to have very little understanding of mental retardation. In many cases the parents of the retarded child appeared mentally deficient. Often it was apparent that problems of food, housing, finances and the other aspects of survival were so pressing that the responsible adult could not be expected to run the gamut in trying to find resources for their mentally retarded child. Of necessity their primary interest had to be that of survival.

The multi-problem families will have to have help in solving many other problems before they will be able to utilize help in understanding mental retardation. In most cases, aggressive casework services seem indicated. This casework should help the family solve the major problems that absorb time, money and thought so that the family can then better use the tools and services available for the retardate.

During many of the interviews, the parents expressed confused feelings for their retarded off-spring. Seemingly, years of frustration and anxiety about the welfare of their families have robbed many of the incentive for improvement. This type family would profit from periodic visits from the staff of the residential institutions for the purpose of giving them support and answers to their many questions regarding their child.

Many parents complain that they have never received data and other important information concerning evaluations from Clover Bottom Hospital personnel (as had been promised). Perhaps this is one of the results of under-staffing at the institution. However, the interviews demonstrated that this type of communication could be of tremendous importance to the families.

People who have placed their sons and daughters in private institutions have refused to remove their names from the Clover Bottom waiting list. Generally they feel that Clover Bottom is a more permanent institution and would be more economical than the private institution. If Clover Bottom personnel were to visit with these people and explain that patients who cannot afford care need these vacancies and that there are other resources in the community, some of them might remove their children's names from the waiting list.

Of course, much of this would depend upon the adequacy of community resources. Virtually no resources were found to be available in the community for the applicants who were more than thirteen years of age and non-educable. It was found that in the area of day-care centers the professionals in the community continue to feel that the non-educable should be institutionalized if they are not able to learn. Obviously such an attitude deters church groups, community organizations or private individuals from establishing day-care centers that would give the non-educable retarded some training and relieve exhausted parents for a few hours each day or each week.

Another community resource, sheltered workshops, were not available to most of those on the waiting list. Only one capable workshop was found in Davidson County - Goodwill Industries. Vocational Rehabilitation had discontinued their use of Handicappers apparently because Handicappers places more emphasis on material output than on the unique requirements of the individual. In Chattanooga, the Orange Grove Center provides not only formal training but also a workshop which is not physically taxing for the retarded. It is oriented toward the severely retarded. The study of the waiting list indicates that such a facility is needed for Metropolitan Nashville.

Also, the need for family counseling and for better evaluation of the abilities and conditions of the retarded on the waiting list was apparent. During the waiting list study, the Peabody Picture Vocabulary test was given but the results are questionable since sufficient time was not available to discuss their child's evaluation in the interview but so little time was available for this that the parents benefitted little. It is possible that they were left even more anxious than when the worker arrived.

Finally, where emergency cases were discovered during the course of this survey, these were taken into Clover Bottom as early as possible. The authorities at Clover Bottom and at Greene Valley make an effort to caution parents of retarded children on the waiting list to notify the Social Security Department of that institution, immediately, if an emergency arises in the home. When such notice is received the standing policy is to promptly accept the "emergency" case as soon as a vacancy occurs which would allow the taking of the applicant.

One of the most frustrating problems pointed up by this study was what to do for those retardates who are on the list but seemingly do not belong to an institution. This is aggravated by the absence of local services available, especially for those retardates classified as moderately retarded.

VIII. Recommendations

1.) Each residential institution of the State should conduct periodic reviews of its waiting list. This should include annual or semi-annual interviews with the family of each person on the list not only to determine the status of the applicant but to advise the family regarding alternate services, sources of aid to help solve economic and related problems, and to educate them to a better understanding of retardation. Supplementary reviews should be conducted to assure that the addresses are up-to-date and that there is a record of those who die or move away.

2.) More aggressive casework service should be made available to the families of applicants for institutional care.

3.) Families of applicants for institutional care should be assisted in finding day care and temporary residence (up to two weeks) for the retardate so the families can rest or take needed vacations.

4.) Professionals involved with day care work should be made aware of the value and need for day care facilities for the retarded.

THE ROLE OF VOLUNTEER ORGANIZATIONS

This chapter is based on the report of The Problem Study Group on Volunteer Organizations

ROLE OF VOLUNTEER ORGANIZATIONS

"Volunteer Organizations" refers to organizations of those who volunteer to work with the retarded or their families. It is obvious that a broad and inclusive definition is needed since the concept must encompass organizations devoted exclusively to work with the retarded as well as organizations which may have a single project for the retarded on a one time basis. Organizations which work only for the retarded include The National Association for Retarded Children, Tennessee Association for Retarded Children and Adults, and local associations for retarded children. Churches, local units or chapters of the American Red Cross, and civic or service clubs are representative of organizations that may provide services for the retarded continuously or for a single project.

The National Association for Retarded Children (NARC) was organized in the early 1950's. (Its mailing address is 420 Lexington Avenue, New York, New York 10017). The stated objectives and purposes of NARC include the following: promoting the general welfare of the retarded of all ages everywhere; encouraging prevention, research, and study in mental retardation; fostering better understanding of mental retardation by the general public and cooperating with all public, private, and religious agencies at all levels; furthering the training of personnel for work with the retarded; encouraging the formation of parents groups; and serving as a clearinghouse of information for and about retardation. The success of NARC is reflected by increased federal and state legislation and support for the retarded in recent years. In addition to a central office staff NARC has established regional offices with representatives and other personnel to help state and local associations for retarded children with their problems.

Under the leadership of a member of the NARC Board of Directors, 65 parents of retarded children met at Peabody College in Nashville on July 19, 1952 and formed the Tennessee Council for Retarded Children. Thereafter local ARC's organized in the principal cities of the state. Renamed the Tennessee Association for Retarded Children and Adults in 1961, the organization now includes 39 member units with some 2,000 individual members. With a few exceptions, each local ARC covers a county. The purposes of the state organization and of each local ARC parallel those of NARC.

A basic policy of NARC and its member units is to encourage tax-supported agencies and volunteer groups to provide the special services required by the retarded rather than for the ARC's to devote their limited resources to providing such services. Initially, however, special services were so lacking that many ARC's undertook the job. They organized special classes, provided classrooms, teachers, and funds to defray the costs. Today, the special classes are operated by the local schools, but in the more rural counties the ARC's often find it necessary to assist by providing station wagons to transport the pupils and by supplementing the teacher's salary.

Because of the basic NARC policy mentioned above, many civic organizations have become the sponsors of services for the retarded that range all the way from pre-school classes to teen-age parties. Some of these originate at the local level but others originate at the state or national level of the civic organization. Civitan International was the first of the major civic clubs to adopt retarded children as their Number 1 nationwide project. United Commercial Travelers next adopted retarded children as a major program. The Jaycees and Jaycettes have long been active for the retarded and recently took on two additional projects: helping to organize more ARC's and helping to find jobs for the retarded.

Other organizations have been providing services to the retarded for years. Religious groups have long provided training for the retarded in regular programs and more recently in special groups. Some denominations (probably none in Tennessee) have established residential homes and schools for the retarded. Other religious bodies have conducted day school programs for the retarded, and some have made their physical facilities available for volunteer agencies to have weekday classes for the retarded. Examples of what other organizations have done for the retarded will be discussed further along in the report.

With the exception of the volunteer organizations that have national and state groups, other organizations concerned with the retarded function on a local or regional basis often through a board of directors which sets general policy with committees responsible for implementing policies determined by the directors. Some organizations have a paid staff which varies from part-time, and perhaps temporary, clerical or secretarial personnel to full-time professional trained employees who provide a wide range of services for the retarded.

At times questions may be raised about the need for volunteer activities when local, state, and federal governmental agencies have large budgets and trained personnel to work with the retarded. Even though volunteer organizations have obtained or provided direct services for the retarded and given consultation for advisory and planning functions, perhaps other activities have been more productive ultimately. It is impossible to estimate the influence which has resulted from their richly rewarding "thinking" following group study, programs, discussions, and projects with the retarded. Stimulating questions are often raised by volunteers which lead to easier or better ways for carrying out specific procedures with the retarded. In addition, increased information and improved public relations resulting from participation in volunteer groups lead to a broad base of support for needed and progressive legislation in retardation. The rapid gains made for the retarded since 1950 are associated with the increasing numbers of both volunteers and volunteer organizations who communicated their interest in retardation to legislative bodies.

Volunteer organizations are in a position to innovate, activate, complement, and supplement services for the retarded since, in general, they are fairly autonomous. They also have more policy freedom in the disbursement of funds than governmental agencies. Volunteer organizations are usually approachable for sponsorship of local projects since their officers and leaders are sensitive to and aware of local conditions and needs. In other words, it is often easier to implement programs for the retarded with volunteer groups than through governmental agencies.

Programs or services for the retarded which are provided by volunteer organizations may have some problems and disadvantages. Program continuity may be hampered by differences in the effectiveness of fund raising campaigns from year to year. Some extremely worthwhile programs suffer from tenuous financing which may interfere with recruitment of personnel for professional positions. In some cases volunteer organizations (like public agencies) duplicate existing services for the retarded by failing to coordinate and cooperate with other groups. Volunteer organizations may become "clique" instead of people or service oriented. These difficulties can be overcome or minimized by adequate surveys of community needs and services and coordination with existing health, education, welfare, and volunteer agencies along with a necessary but often overlooked requirement to obtain expert professional advice for professional matters.

I. VOLUNTEER ORGANIZATION SERVICES FOR THE RETARDED

There is an impressive array of services available to and for the retarded in different communities over the state. Equally impressive is the lack of information generally available to describe existing programs and projects. Professionals in retardation often do not have adequate information about various programs for the retarded and other handicapped to make the most appropriate recommendations for particular situations. Some information is available in urban areas through health and welfare planning councils, but written materials may be several years old. Local ARC units submit reports on projects in their area to the state association , but many Tennessee counties do not have organized and active ARC units as yet. A complete survey of all services for the retarded in Tennessee with provisions to update the information at stated intervals would assist in planning and initiation of needed programs. A directory of services hopefully would include volunteer organizations and governmental agencies.

It is impractical for this report to give a detailed list of all volunteer organizations which have provided services for the retarded and to list all the different services that have been or are now offered. Also, it is difficult to set priorities for needed services. The variety of services needed or available in urban areas often differs from the variety of services needed or available in rural areas.

Some needs of the retarded are relatively constant regardless of the location of the individual, category of retardation or chronological age. Other needs are not. For instance, transportation for the retarded and their families to obtain diagnosis and treatment for the retardate and counseling for the family may be a very urgent need in rural areas but less urgent in urban areas. Likewise, the service needs of retardates residing at institutions are not always the same as for those residing in the community. There are also obvious differences in the service requirements for the profoundly and severely retarded in contrast with the mildly retarded. Equally important, different service needs are found among the retarded in terms of chronological age. As a result priorities will vary from community to community and from time to time.

The foregoing statements are more easily understood if you look at the chart in §4 of Chapter 1 which shows the array of direct services to the retarded. This array of services was described as "continuum of care" by the president's panel on mental retardation on page 74 of its report:

> Continuum of care' describes the selection, blending and use, in proper sequence and relationship, of the medical, educational, and social services required by the retarded person to minimize his disability at every point in his lifespan. Thus 'care' is used in its broadest sense and 'continuum' underscores the many transitions and liaisons, within and among various services and professions, by which the community attempts to secure for the retarded the kind and variety of help and accomodation he requires.

Some elaboration and extension of the panels' description of "continuum of care" is desirable since it made no provision for diagnostic and evaluation services or for services to the family of the retardate. The remainder of this chapter will discuss the role of volunteer groups in prevention, diagnosis and the array of direct services in the continuum of care and will describe some of the service volunteers have furnished. Services of volunteer organizations that are cited are given as illustrations only and are not intended to suggest that the illustration given is the best or most efficient way to provide the service.

Prevention of retardation is a goal of all associations for retarded children at all levels - local, state, and national. A portion of all support money sent to NARC by local units and funds raised by special campaigns are devoted to research. Research funds are provided for both applied and basic research, and some sponsored scientists are investigating ways to prevent retardation.

Prevention of retardation may be possible in some instances by early and continuous prenatal care accompanied by an adequate diet for all pregnant women, infants, and young children. Volunteer organizations such as churches, home demonstration clubs, and settlement houses could encourage the dissemination of information concerning good prenatal care, make referrals for care as indicated, and provide information about dietary requirements for pregnant women and children. Some volunteer groups provide milk and other nutrients for disadvantaged families. Volunteers might also supplement available funds for special diets required for some children with metabolic disorders.

Hopefully diagnostic services will become available to all retardates at the earliest possible time that reliable and appropriate evaluations can be made. Although these services may usually be available at a cost that varies with the ability to pay, allied costs might be prohibitive for some families. Such costs might include transportation, living expenses for the family while they are away from home, and baby sitter fees for the care of siblings. Volunteer organizations could underwrite these costs for families who need financial assistance. Trained volunteers might facilitate early recognition of retardation by using screening procedures with infants and young children in centers that serve large numbers of infants and young children from disadvantaged homes such as well-baby clinics.

Differential diagnosis to distinguish mental retardation from autism, aphasia, and profound hearing loss is extremely difficult. Realistically such diagnosis is enhanced by long term observation combined in some cases with variation in treatment which can be carried out more efficiently in a residential setting. Volunteer groups could sponsor or partially support such a project.

Since mental retardation is usually considered "incurable" and other handicapping conditions are often associated with it, treatment services for physical, neurological, and emotional problems should be available for all retardates. Again, transportation costs and associated charges could be provided by volunteer organizations as needed. Seizure control drugs are furnished to some families by volunteer groups.

Shelter, nurture, and protection are required outside the parents' home for some retardates. Virtually all states have sizable waiting lists for residential placement, and there is sometimes a desperate need for interim care for all ages. The need for such care may be either transient or long term and may result from a variety of circumstances. Volunteer organizations have approached this problem in a variety of ways. Some religious groups, service clubs, and ARC units have built and maintained residential facilities. Other groups have provided financial support for residential facilities, and other organizations have given partial or full support for the maintenance of one or more retardates who are placed in private facilities. Another approach has been to locate and finance foster home care for the retarded. Some volunteer agencies may want to consider sponsorship of half-way houses for retardates who are reentering society after residential placement or for trainees and employees in sheltered workshops. Volunteer organizations may offer homemaker services for some families with a retarded child. A homemaker can provide relief for a harried mother, may assist in the development of better child rearing practices, or teach more efficient housekeeping methods. The goals and procedures of homemakers are variable but generally flexible so their use has wide applicability.

The philosophy of universal education and training for all children notwithstanding, public education and training for all retarded children are goals that have not been reached. Classes for the retarded started by volunteer organizations have encouraged the formation of classes for the mentally retarded in the public schools. Volunteer organizations are still operating classes for trainable and educable retardates in some areas where the school districts do not qualify for state aid for various reasons. Volunteer groups are also extending services to other retardates who are not eligible for public school attendance under existing regulations. These programs may be day care centers which stimulate self-care activities and give rest to mothers of severely and profoundly retarded children. Some volunteer organizations provide other training services such as speech and language therapy. Research has suggested that behavior therapy or behavior modification through "shaping" and reinforcement techniques can be extremely helpful in establishing self-help activities and in the elimination of undesirable behavior patterns. A "live-in" center for short term behavior therapy may be a laudable project for volunteer organizations. Volunteer groups have given many scholarships to encourage training for professional personnel to work with the retarded.

Recreation for the retarded has been the exclusive domain of volunteer organizations in some areas. Among other groups the churches, Boy Scouts, and Girl Scouts have made special provisions for recreation with the retarded. Some organizations have sponsored dances, entertainment, and outings and provided opportunities for the retarded as both participants and spectators in sports. Additional efforts are probably needed to reach more adult retardates who are partly or fully self-supporting to help them make effective use of their leisure time. Camping programs are available to many retardates through volunteer groups who provide facilities, personnel, or financial support. More churches should be encouraged to provide Sunday schools and other programs for retardates.

Vocational or job training of the retarded is a tradition in some areas. Goodwill Industries and sheltered workshops supported by volunteers have demonstrated that the retarded are employable. Since sheltered workshops may provide for job training and for terminal employment, the help of volunteer agencies has been solicited to provide employment opportunities for trained and qualified retarded workers. NARC, TARCA, and some ARC units give employer of the year awards to employers who have done outstanding work in employment of the retarded. The North Carolina Junior Chamber of Commerce has made systematic efforts to obtain employment for the retarded through its "Project JOB." Regional offices of the Division of Vocational Rehabilitation can always use additional training positions or employment for the retarded.

II. VOLUNTEER ORGANIZATIONS SERVICES TO THE RETARDED IN INSTITUTIONAL SETTINGS

Residential homes, schools, and hospitals as well as day schools and day care centers provide unique opportunities for volunteer agencies to work with and for the retarded. In addition to the usual projects of providing extras for the residents, students, or patients through financial support, there are many other services which can be carried out by volunteer groups. For example, volunteers may give parties in wards or cottages, write letters for or to the retarded (It is both heart-rending and soul-satisfying to see the enchanted look on a retardate's face when he proudly shows his creased, ragged, finger marked letter or card from his sponsor.), provide supplemental clothing or incidentals, feed a physically involved child, or simply talk with a retardate in a residential setting. Even though some institutions for the retarded have a chaplain on the staff, volunteers are often encouraged to give time for religious instruction. Other volunteers may be used in a variety of jobs which include clerical tasks, help in the canteen, instruction in craft and hobby activities, or work in recreation in the wards or cottages.

III. GUIDELINES FOR AND SOURCES OF VOLUNTEERS FOR SERVICE

Volunteers for personal service with the retarded perform important functions in residential facilities and schools, and several volunteer organizations including the American Red Cross with its Gray Lady program have developed guidelines which are useful in working with volunteers for service. IT IS MANDATORY THAT THE ADMINISTRATIVE AND LINE PERSONNEL WANT VOLUNTEER ASSISTANCE AND THAT THEY DETERMINE THE NEED FOR AND DEVELOP SPECIFIC JOB DESCRIPTIONS FOR EACH ACTIVITY ASSIGNED TO VOLUNTEERS. At least one and sometimes several staff coordinators should be appointed to work with volunteers. The volunteer group or organization needs a chairman or spokesman for representation at the facility. Volunteer organizations should be recruited for particular functions. Suitable volunteers are selected and trained for the service they are expected to perform. Their performance is evaluated periodically and systematically by the volunteer organization and the facility staff. An important aspect in voluntary programs is the provision for individual and public recognition of service by volunteers which can range from the presentation of pins or certificates to represent hours of service to a regular and formal volunteers recognition day program.

The shorter work week for many workers has increased the number of leisure time hours which are now available for volunteer work with the retarded. There are several obvious sources for volunteers who can work with the retarded. Many organizations which serve the retarded encourage or require parents to participate in various ways. Professionals can often be enlisted as volunteers by recruiting nonworking married women who are trained as nurses, teachers, social workers, etc.

Retired professionals and other retired persons (some military personnel are quite young at retirement) offer another source for volunteers. College students who serve as volunteers with the retarded are excellent prospects for training as professional workers in retardation. High school students have been trained for volunteer work in some residential facilities. At least one volunteer organization has offered orientation and training for teen-agers to serve as baby-sitters for the handicapped including the retarded. In one urban area there is a volunteer service bureau operated by the planning council for health and welfare agencies which registers volunteers and refers them to the organization which seems most appropriate for them.

IV. CONCLUDING STATEMENTS

When a specific need of the retarded is recognized by responsible persons in the community, volunteer organizations are usually available to sponsor a project or provide a service. The variety of organizations that support projects in residential facilities attests to the changing attitudes and increasing public acceptance of retardation in the community, state, and nation.

Specific discussion of fund raising by volunteer organizations working with the retarded has been avoided because the methods and procedures for raising money varies greatly from organization to organization and from community to community. Three comments, however, do seem appropriate. First of all, fund raising for projects with the retarded should always be accompanied by materials or presentations which inform and educate the public about retardation. Secondly, fund raising should use dignified approaches and avoid exploitation of the individual retardate. And thirdly, all volunteer organizations working with the retarded should maintain adequate records of receipts and disbursements to meet or exceed acceptable accounting practices.

RECOMMENDATIONS

1.) There is an urgent need for a statewide survey of services available to and for the retarded and their families from volunteer organizations and governmental agencies. Procedures need to be developed to keep the information accessible and current. Closely allied is the need for realistic recognition of unmet needs of the retarded and their families at the community and state level so that the gap between resources and unmet needs can provide a constant stimulus for additional services.

2.) Equally obvious is the need to encourage coordination and cooperation of volunteer organizations and governmental agencies which provide services for the handicapped. Coordination and cooperation is needed at all levels. The State must offer leadership to encourage this needed coordination and cooperation.

3.) The State needs to hire people - preferably trained in community organization to stimulate activities of volunteer organizations for the retarded in each of the three major geographic divisions of the state.

4.) The State needs to work with the Tennessee Association for Retarded Children and Adults in organizing local associations for retarded children, in all counties where no local ARC now exists.

5.) Representatives from a cross-section of welfare, medicine, education, religion, and volunteer groups should organize state and county (or regional) committees for an on-going study of facilities, services and needs of the retarded.

6.) A compensation process should be developed, perhaps through insurance companies, to give medical care for accidents and injuries sustained by volunteers while they are working with the retarded, and to provide for compensation to persons (retardates and others) who suffer injury or property damage because of the negligence of volunteers. This is especially important where volunteers are furnishing transportation.

7.) Well-baby clinics and other centers serving large numbers of infants and young children should try to develop screening procedures operated by volunteers to facilitate early recognition of retardates.

8.) As evaluation and diagnostic facilities become available volunteer organizations should be urged to assist in providing transportation, transportation costs, baby-sitting services and living expenses for families who must take retardates long distances to be evaluated or are required to stay with the retardates during the evaluation period.

9.) Volunteer groups should be encouraged to offer home-maker services for families with retarded children, to relieve the harried mother, and to teach more efficient housekeeping methods and child-rearing practices.

10.) As the residential facilities improve their evaluation and training methods to the point that some residents are able to try to reenter society, volunteer agencies should consider providing half-way houses to help these retardates go from the institutional environment to the open society environment.

11.) Institutions must make a place for volunteers. Both the administrative and line personnel must welcome volunteer assistants, clearly develop and describe jobs assigned to volunteers. Where possible these jobs should include visits by volunteers to give parties, write letters, give religious instruction, assist in recreational, craft and hobby activities. Where nurses, secretaries, social workers and othe professionals are available, institutions should utilize their talent as fully as possible. Every institution should have a volunteer representative at staff or faculty meetings.

12.) All institutions and organizations dealing with retardates should devise programs for giving public recognition for outstanding volunteer work.

PREVENTION *

* Note - No special problem study group was assigned Prevention as a separate subject of investigation. The material submitted here was extracted from reports of several problem study groups or supplied by the editing committee. It is inserted by authority granted by the Advisory Council on Mental Retardation.

PREVENTION

In the field of action to combat mental retardation one stark reality must be faced at the beginning. That is, at the present stage of our knowledge most forms of mental retardation cannot be prevented from occurring. We do not yet know even all the causes of retardation and the some two hundred odd causes we do know about would seem to account for only about 5% of the cases of retardation. On the other hand, we do know of causes that we are able to cope with or should be able to equip ourselves to cope with.

For example, it is generally recognized that a very high percentage of the retardates are found in low socio-economic environments. The precise factors in these environments that produce retardation have not been clearly isolated or identified. For this reason we presently must denominate these environments as high-risk areas as is more clearly set out in the chapter on Case Finding. This is a very promising area for accelerated research. All of the committees urge both the physical scientists and the behavioral scientists be alerted to the need for further investigation of the relationship between low socio-economic environment and retardation.

Familial patterns likewise offer clues that can lead to preventing retardation before it occurs. Here again we have not utilized these clues for preventive purposes as well as could be because their importance has not been fully appreciated or a systematic program of recognition, evaluation and follow-through has not been devised and executed.

Some forms of Down's syndrome (mongolism) are known to be hereditary. Where a mongoloid is born into the family, especially in the earlier years of marriage, genetic and birth control counseling is often indicated since there is a definite possibility that mongoloids will occur in subsequent generations.

Phenylkeponuria (PKU) is another condition which if undiscovered and untreated can lead to retardation. This condition can be discovered by testing the new born. The condition can be avoided by genetic counseling or the retardation produced by the condition can be avoided by treatment of the new born infant. It is also clear that there are many other conditions similar to PKU which may be treated or avoided in the same manner.

There is a strong relationship between mental retardation and pre-natal care. Every mother must receive the best possible pre-natal care. The first three months of pregnancy are especially important. It is important that the expectant mother not be exposed to certain drugs during pregnancy and also that her general health and nutrition be protected. Thousands of expectant mothers do not see a physician until late in pregnancy. This must be avoided.

In some of our rural areas and in the lower socio-economic environments the conditions of birth itself leaves much to be desired. Many things may occur during the birth process which lead to mental retardation. This is not only a problem in cases of mid-wifery but the problem also arises in small hospitals that are not sufficiently equipped or staffed to meet and cope with emergencies at birth which, it not properly handled, can precipitate retardation.

Infectious diseases can cause retardation both before and after birth. If a mother suffers from rubella (German measles) during the first three months of pregnancy the likelihood that the child will be retarded is sufficient that some states permit abortion. It is also known that another form of measles (rubeolla) is to be avoided in children because of the risk of brain dysfunction. Every child should be immunized against rubeolla. The immunization is simple and inexpensive and is available both in the Public Health Clinics and from the private physician. We are already conducting public information programs to promote rubeolla immunization but the urgency of the message is not getting across to many of our parents. Other infectious diseases, including venereal diseases, are associated with retardation and this message needs to be told both to the general public and our professionals.

Appropriate child care is also important. Proper nutrition is considered to be important to the development of all children. Obviously child abuse can lead to injuries both physical and psychological that can cause or aggravate retardation. Tennessee has recently enacted new laws to lead to quicker discovery and better handling of child abuse and child neglect as well. All persons working with juveniles as well as the community in general need to be alerted to the importance of discovering cases of child abuse and child neglect promptly and acting firmly to see that it does not continue or recur in any individual case.

Another closely related matter is accident prevention. Any program of mental retardation prevention should give support to accident prevention programs.

Some evidence seems to support the hypothesis that milder forms of retardation can be avoided by early environmental stimulation of the child and his learning processes. Head-start programs can be meaningful here. Also, in the chapter on Special Education recommendations are made for enriching the learning opportunities of pre-school children both by parent education and by community programs.

There is another side to the prevention picture. As previously stated, many of the causes of retardation are unknown and many of those that are known cannot be avoided. Nevertheless, we do know how to prevent some of the more drastic consequences of retardation. In fact, the main thrust of the over-all program envisioned by this report is directed at preventing unnecessary consequences of retardation. This can be done by insuring that the retardate will have an opportunity to develop to the fullest extent of his capacities, by removing the stigma and mystery that the public has in the past associated with the retardate, and by equipping parents, relatives and others who are close to the retardate so that they can better cope with the problems of the retardate as well as their own problems.

It is intended that every section of this report serve to relieve our society both individually and collectively, of the unnecessary consequences of retardation and the proposals should be tested in light of how well they would or would not accomplish this aim.

On the following page is a chart for identifying high risk infants which is a good index to areas where strengthened procedures for preventing retardation or its avoidable consequency are indicated.

RECOMMENDATIONS

1.) Physicians, public health nurses, social workers and other professionals need to be kept acutely aware of the opportunity for identification of the retarded signaled by such things as infection, RH factor incompatibility, chromosomal disorders occurring in the history of patients or their relatives.

2.) The Department of Public Health should assume the responsibility for seeing that no mother shall be denied needed pre-natal care and training. The Department of Public Welfare and other welfare agencies should be actively involved in this prenatal program.

3.) Mandatory minimum standards and procedures need to be established by law to assure that all delivery facilities are able to cope with birth emergencies that could produce retardation.

4.) Public and professional information programs reminding professionals and the general public that avoiding infectitious diseases such as rubella, rubeolla, and others can be an effective means for preventing some forms of retardation. Parents of mongoloids should be given genetic and birth control counseling.

5.) The State should legally require that all infants be tested for PKU and as tests for predicting other forms of retardations are developed and refined the State should consider making them mandatory also.

*High-Risk Infants

Where There Is a Family History Of:

- Presence of Mutant Genes
- Central Nervous System Disorders
- Low Socio-Economic Group
- Previous Defective Sibling
- Parental Consanguinity
- Intrafamilial Emotional Disorder

Medical History of Mother:

- Diabetic
- Hypertension
- Radiation
- Cardiovascular or Renal Disease
- Thyroid Disease
- Idiopathic Thrombocytopenia Purpura

Previous Obstetrical History of Mother:

- Toxemia
- Miscarriage Immediately Preceeding Pregnancy
- Size of Infants
- High Parity
- Prolonged Infertility

Present Pregnancy:

- Maternal Age Less than 18 or Over 38
- Multiple Births
- Polyhydramnios
- Pyelonephritis
- Out-of-Wedlock Pregnancy
- Oligohydramnios
- Medications
- Radiations
- Anesthesia
- Maternal Rubella in First Trimester
- Diabetes
- Toxemia
- Fetal-Maternal Blood-Group Incompatibility

Labor and Delivery:

- Absence of Prenatal Care
- Prematurity
- Postmaturity-Dysmaturity
- Precipitate, prolonged or Complicated Delivery
- Low Apgar Score - 15 min.

Placenta:

- Massive Infarction
- Amnion Nodosum
- Placentitis

Neonatal:

- Single Umbilical Artery
- Jaundice
- Head Size
- Infection
- Hypoxia
- Severe Dehydration, Hyperosmolarity, and Hypernatremia
- Convulsions
- Failure to Regain Birth Weight By Ten Days
- Manifest Congenital Defects
- Disproportion Between Weight Or Length and Gestational Age
- Survival Following Meningitides Encephalopathies, and Traumatic Intracranial Episodes

*MENTAL RETARDATION: A HANDBOOK FOR THE PRIMARY PHYSICIAN, AMA 1965

CASE FINDING, DEFINITIVE DIAGNOSIS AND EVALUATION

This Chapter is Based on the Report of
The Problem Study Group in Case Finding

Case Finding, Definitive Diagnosis and Evaluation

Case finding simply means the identification of retardates not presently known to be retarded. While the importance of early and comprehensive diagnosis of the existence and degree of retardation cannot be overestimated, at present this is the weakest link in the chain of services for the retarded in Tennessee. Because the mildly retarded at first appear to be normal, periodic and meticulous scrutiny of their growth and development is necessary for early detection. The following plan for the identification of retardates is concerned primarily with this group because the mildly retarded comprise an estimated 85% of all retardates and can, with a proper program of education, care and training, participate productively in society. The proposed "Blueprint for Action" in this chapter is organized along two main dimensions, first, by chronological age of the retardate, and second, by immediacy of goals - immediate, intermediate, and long range.

I. PREBIRTH PREDICTION

The task of identifying the mentally retarded starts before birth. As indicated in the introduction, certain known causes of retardation - infections, medicine and drug problems, RH factor incompatibility, chromosomal disorders and other causes - are all danger signals that warn of an increased possiblity of resulting mental retardation.

Recommendations

The physician, public health nurses, social workers, and other professional persons need to become and remain acutely aware of the importance of these danger signals and of the opportunity that they give for early identification of the mentally retarded or actual opportunity for preventing retardation.

II. BIRTH TO THREE YEARS

The prime responsibility for early identification of the mentally retarded infant rests with those members of the profession who observe the child during the first three years. This includes the pediatrician, the family physician, the public health nurse, the social worker and the psychologist. However, these professionals need special and continuing training regarding prevention, early detection, diagnosis and follow-up of potential retardates. The various state departments charged with responsibilities for the retarded in cooperation with other agencies and organizations, both professional and voluntary, should provide leadership in seeing to it that these professionals are aware of and utilize the most recent information and instruments for the detection of possible intellectual deviations.

As indicated, some children of all socio-economic groups are considered "High Risk" because of the family history, the medical history of the mother, or the presence of other conditions which experience has shown are often associated with retardation. There is disproportionately high incidence of mental retardation among children born into certain segments of Tennessee's population because of associated economic, educational and cultural reasons. Most attention should be given to all infants in these "High Risk" groups.

Recommendations

A. Immediate Goals

1.) Every child, regardless of the parent's financial status, should be screened soon after birth for metabolic disorders, e.g., phenylkeponuria, galactosemia, and maple syrup urine disease.

2.) The Department of Public Health should make rules pertaining to screening tests for metabolic disorders.

3.) The name of every child found to have a metabolic disorder should be reported to the Public Health Department for follow-up.

4.) The Department of Public Health and other state departments should cooperate with the attending physician to provide continuing medical and dietary care for any child suffering from a metabolic defect.

5.) Upon discovery of a case of retardation familial in origin, the Public Health Department should perform diagnostic procedures on all other members of the immediate family.

6.) Birth certificates should be completed prior to discharge from the hospital, or in the case of home delivery, within ten days. The attending individual at birth should be responsible for preparing a complete and correct birth certificate.

7.) Improved communications between the State Department of Public Health, local health departments, private practitioners, medical schools, the Department of Education, the Public Welfare Department, and the Mental Health Department, should be effected, especially regarding the preparation and use of birth certificate information.

8.) Parents must be informed that services for mentally retarded children are available and must be urged to seek medical evaluation if their children do not seem to be progressing normally.

9.) Emphasis should be placed on training social and welfare workers to recognize early symptoms of mental retardation in young children.

B. Intermediate Goals

1.) The committee established in the State Public Health Department should adapt the "New Birth Certificate" for use in Tennessee in order that "High Risk" infants may be identified in a confidential medical data section and should then promote its acceptance and use by physicians.

2.) Continuous health supervision or observation should be exercised over children reported in the "High Risk" category.

3.) Health Departments throughout the state should cooperate with family physicians to insure that "High Risk" children are given priority in obtaining all necessary services.

C. Long Range Goals

1.) Every child should have the opportunity for continuous health supervision through the cooperation of the practicing physicians in Tennessee and the State Department of Public Health.

III. THREE YEARS TO FIRST GRADE

Three years is a particularly crucial age for mildly retarded persons, for not until then can they be identified by psychological means. At present, most of the mildly retarded at age three are headed for progressively increasing manifestation of retardation. However, this can be averted by the implementation of the following recommendations because the retardate at this age is sufficiently young and modifiable to permit further intellectual growth.

Recommendations

A. Immediate Goals

1.) Kindergarten should be made a part of the public school system with attendance compulsory at age six and desirable at age five. Kindergartens, which have as their main purpose the evaluation of the child's readiness for school, can play a major role in case finding.

2.) School readiness tests should be given in April of the kindergarten year with referral for definite diagnosis of those found not ready for school.

3.) The summer pre-school headstart program should be extended downward to include the deprived four year old.

B. Intermediate Goals

1.) The summer headstart program should be extended to include deprived, three year olds.

2.) All children should be compelled to register at school age with an immediate follow-up of all children who then do not appear for classes.

3.) In June there should be an annual TV campaign on growth and development patterns of three year old children. A check-list form should be mailed to known parents of children of this age and should also appear in the newspapers. The check -list would instruct the parents to see their private doctor or the Board of Education if their child scored below a certain level.

4.) A grant for developing an instrument suitable for mass screening of three year olds should be made.

C. Long Range Goals

1.) A state data center should be established with responsibility for accumulating data from all the state departments involved in the mental retardation program.

a.) At birth -
    (1) a data card with birth information would be filed.
    (2) a Social Security number would be designated.
    (3) a change of address card and a developmental score card would be mailed to the parent with the necessary instructions.
b.) At age three -
    (1) the cards of all children this age would "drop down" and their parents would receive the necessary information and materials for a check-list growth and development test. The TV campaign mentioned on C3 above would coincide with this test.
    (2) local school boards will conduct a follow-up of the parents not returning the above tests.
    (3) low scorers would be screened out for further diagnostic study, with a letter sent to the parents saying in essence "consult your physician". A duplicate letter would go to the school board for follow-up.
    (4) provisions should be made for "picking up" newcomers in the community.

IV. FIRST GRADE TO SIXTEEN YEARS

It is now generally accepted that even mild retardation can be detected by school age. In Tennessee, however, only a small percentage is presently being identified promptly at the first grade level for several reasons. First, only about 25% of the children entering school are given readiness tests, and of those tested and adjudged "not ready" only a small minority are referred for further professional study. Secondly, in some areas of the state, a child must fail a grade twice before he is given psychological tests.

Recommendations

1.) Every child entering the first grade should be given readiness tests and those adjudged "not ready" referred for complete evaluation.

2.) Group IQ tests, both verbal and non-verbal, should be administered to all children by the fourth grade.

3.) All children should be referred to the pupil personnel services for further study upon their failure to complete satisfactorily any grade in school.

4.) There should be an immediate referral of the name of all "drop-outs" to the Division of Vocational Rehabilitation in order that evaluation, guidance, and training may be immediately instituted.

V. THE ADULT RETARDATE

Once a retardate is beyond the school years, if he has had good school placement and job counseling and placement, he becomes less conspicious in our society. Nevertheless, he still needs to be known in order that needed services can be rendered him. If the recommendations of this committee are implemented for child retardates, we believe that within a few years there will be a smaller percentage of adult retardates who will need services.

For the adult retardate today the most prepared and logical agency to do that is the Division of Vocational Rehabilitation, Department of Education. This agency now operates a network of ten vocational centers for the mentally retarded (and other handicapped individuals) and expects to expand these workshops in the future. At the present time pupils, school drop-outs, rejectees of employment security, rejectees of Selective Service, and applicants for Social Security benefits, and others are all referred to the Division of Vocational Rehabilitation.

Recommendations

1.) When the Department of Education over the State expands its pupil personnel services, the Division of Vocational Rehabilitation should have access to the diagnostic findings of that resource and thereby hasten vocational planning.

VI. DEFINITIVE DIAGNOSIS AND EVALUATION

The concern to this point has been with mass screening, or the finding of suspected retardates. This is the first step in a program for the mentally retarded. The next step is a comprehensive diagnostic evaluation. Until this is done no treatment or training program can be undertaken safely. It is imperative that case finding be supplemented by greatly expanded facilities in Tennessee for thorough and comprehensive diagnosis employing the skills and contributions of several professions. Ideally, such an "interdisciplinary" or "multi-disciplinary" evaluation would include:

1.) A medical examination including a physical examination and a family medical history to determine the present medical picture and to reveal the possible etiology of the condition.

2.) A psychological evaluation to determine the level of intellectual, emotional and social functioning.

3.) An educational evaluation to determine past educational attainments and suitability for further training.

4.) A family social history evaluation to obtain the social constellation of the child and his family.

5.) Program planning for the child.

6.) Counselling the parents.

7.) Referrals to appropriate treatment facilities.

8.) Provisions for follow-up re-evaluations.

In children three years of age and under, the majority of those identified as retarded will be severely afflicted. In these cases the symptoms of retardation are often accompanied by neurological and physical handicaps and the diagnostic problem is primarily a medical one. As is more fully discussed in the Community Care Centers chapter, only the regional centers can be expected to have the array of specialists needed for children of this age.

After age three years the point of emphasis of the diagnostic shifts to problems of a psychological, educational, and social nature; medical evaluation is now only one part of the total evaluation. The principal problems now are assessing the child's capacities, knowledge, and skills in order to plan an appropriate training program. Diagnostic evaluation and counselling services should continue through the schooling, vocational training , and placement periods. This is necessary because characteristics, conditions, and needs change over the years with the intervening treatment and environmental experiences.

VII. MANPOWER AND TRAINING

The expanded programs envisioned in this report will require greatly increased manpower. Recognizing that the supply of highly trained personnel is not endless, the following suggestions recommend the utilization of heretofore untapped manpower sources. With limited training these individuals could perform satisfactorily in certain jobs under the supervision of fully trained personnel. The following recommendations are made to help meet the manpower problems.

Recommendations

1.) Under a planning grant, there should be extensive pilot and demonstration projects to explore the utilization of new manpower resources.

2.) Highly trained professional persons should be employed to devise examinations for use in case finding which can be administered by non-professional persons under adequate supervision.

3.) School teachers available for summer employment could be easily trained to do routine psychometric testing of pre-school and school-age children.

4.) Retired persons and young mothers could be trained and utilized on a part-time basis.

5.) Unpaid volunteers will become more available as the work weeks become shorter and should be actively recruited.

6.) An expanded staff in the Division of Vocational Rehabilitation is necessary to serve adequately the retarded adults throughout the state.

7.) Additional funds must be allocated to the institutions sponsoring training for work in mental retardation.

8.) Tennessee should establish the University Affiliated Training Centers for "physicians and other specialized personnel needed in the field of mental retardation" which are provided for in Public Law 88-164.

PUBLIC AWARENESS

Based On the Report Of

The Problem Study Group on Public Awareness

PUBLIC AWARENESS

Broad public awareness and understanding of mental retardation and its many social and economic implications are essential to insure the needed funds and facilities. Indeed, the whole concept of community care centers and the goal of increased employment opportunities, early detection and evaluation of retardates and the other programs envisioned by this report all depend on public acceptance of the basic proposition that retardates deserve the same, if not more, opportunities to develop their respective capabilities to the maximum which are afforded the normal individual. The public must be made aware of such facts as the scope of the problem, that its effects can be prevented, and that an estimated 75-85% of the retardates are employable after proper training. When the public has been made aware of the true facts about mental retardation, it can be expected that an informed Tennessee populace will support whole-heartedly the public and private programs envisioned in this report.

One of the most baffling challenges to an effective public awareness program for mental retardation arises because nearly every program needed to prevent the avoidable effects of retardation requires coordinated action by social agencies which ordinarily can perform their prime functions with a minimum of dependence on other agencies. Improved lines of communication must be opened between various State departments, between various professionals dealing with retardation, between various volunteer organizations who are primarily or incidentally concerned with retardation and others. This is clearly demonstrated by the programs proposed in the chapter on Case Finding. The action called for in regard to infants in the high-risk groups would require close coordination of the family physician, the pediatrician, local health departments, school teachers, welfare workers, parents, juvenile judges and volunteer organizations among others. Each of these must be aware of their importance to the high-risk program if it is to function with optimum results. Not only must these people have a general understanding of mental retardation but they must be given in-depth training concerning the aims of the program and the vital importance of their particular role. This training must start in the public school system and the colleges.

Surveys made during the course of this study show that there is both minimal information available to and knowledge on the part of the various groups and individuals surveyed on the subject of mental retardation. This was true not only of those with a general college education but also professional persons such as physicians, lawyers, social workers, and law enforcement leaders. While almost 100% of the news media indicated its willingness to cooperate in a publicity campaign, it was also found that they too receive a minimum amount of information to be disseminated to the public.

1. Professional Education and Training

Since professional persons and law enforcement leaders are the persons to whom the retardates and their families turn for advice and otherwise often contact, it is imperative that these leaders be fully and correctly informed. If they are, they can offer valuable guidance and supportive understanding at crucial times of need. Also, their understanding is essential if new laws and new programs, both public and private, are to be properly instituted and effectively carried forward. To determine the extent to which these people are being trained and educated in the area of mental retardation, questionnaires were sent to seventy-six public and private schools, colleges, and universities within the state and forty-eight (63.1%) were returned. Questionnaires were also sent to ninety-three judges of which thirty-seven (39.8%) were returned. Also, one hundred thirteen chiefs-of-police were furnished questionnaires but only twenty-six (23%) responded. These questionnaires were not intended to test the recipient's knowledge of mental retardation, but rather to determine to what extent mental retardation was included in their education or training programs. Based upon the questionnaires returned, the following are of major importance.

Tennessee schools, colleges and universities:

(1) Over 80.0% of the public and private Tennessee schools of higher learning do not offer a course dealing specifically with mental retardation.

(2) Two-thirds of the public and private Tennessee schools of higher education give mental retardation minimal importance by including it as subject matter in other courses of study.

Liberal Arts and General Education Programs:

(1) Less than 10% of the public and private Tennessee colleges and universities having Liberal Arts and General Education programs offer special course in mental retardation.

(2) A little over one-half of the Liberal Arts and General Education respondents include mental retardation as subject matter content in other courses of study.

(3) Psychology courses are more apt to include mental retardation subject matter than are other Liberal Arts or General Education courses.

(4) The course, General Psychology, which is most frequently a general education requirement, usually does not include mental retardation subject matter.

Professional Education Training Programs:

(1) Courses in mental retardation are conspicious by their absence in professional education in Tennessee. Although one medical school reported two such courses of study, no courses were reported by the Schools of Dentistry, Divinity, Social Work, Professional Nursing, and Practical Nursing.

(2) Mental retardation subject matter is incorporated in other courses of study by only two-thirds of the responding public and private professional

schools in Tennessee. Thus, Tennessee professional schools give only minimal recognition to mental retardation as subject matter for study in professional education.

Special Education:

(1) The data confirm the assumption that those schools of higher education with programs in special education, that is, the field of study which deals with the education and training of retardates, offer a variety of courses in mental retardation.

Planning and Expansion:

(1) Only a very limited amount of planning is underway to develop or to expand mental retardation subject matter in Tennessee public and private schools, colleges and universities.

Law Enforcement Leaders

Judges:

(1) Over one-half of the responding judges did not feel equipped to deal with mentally retarded persons.

(2) The majority of the judges who have knowledge concerning mental retardation received their orientation from printed materials.

(3) More than three-fourths of the judges indicated a need for a manual regarding mental retardation.

(4) Almost two-thirds of the judges recommended a short course in mental retardation.

Chiefs-of-Police:

(1) Over two-thirds of the responding chiefs-of-police did not feel equipped to deal with the mentally retarded.

(2) Over 96% of the responding chiefs-of-police had no training in mental retardation and did not have printed materials to guide them in dealing with the retarded.

(3) Over 80% of the chiefs-of-police suggested the need of a manual regarding mental retardation.

(4) Over 90% of the chiefs-of-police suggested the need for a short course in mental retardation.

II. Community Education

Another survey was made to determine the extent to which knowledge concerning mental retardation is available at the community level, to evaluate information channels concerning mental retardation and their utilization at the present, and to recommend more appropriate methods of channeling the information to the community. Questionnaires were sent to Boards of Education, Departments of Public Health, Councils for Retarded Children and Adults and civic organizations throughout the State. Information received from Boards of Education dealt with the establishment of EMR and SMR classes and is included in the chapter on Special Education Services. The other major findings are reported below:

A. Department of Public Health

The validity of the following findings in respect to the public informational work done by the Department of Public Health is seriously put in question by the fact that only 16% responded to the questionnaires. Nevertheless, those findings made are startling.

(1) 60% of the Departments did not have any printed materials to provide parents of mentally retarded children.

(2) 75% in their public school programs did not provide instruction for teachers in the care of retardates while in school.

(3) Over 76% indicated that neither the Department of Public Health nor any other facility in the county provided a parent council group for parents of the mentally retarded.

B. Associations for Retarded Children and Adults

The response from these groups was also disappointing as only twelve of thirty-five (34%) replied. However, based upon the information obtained from these ARC's, it appears that most are presently providing valuable community services. To illustrate, all maintained contact with the newspapers, radio stations, and physicians in their areas. The number of programs which they provided for civic clubs, garden clubs, etc. averaged eleven per year.

C. Civic Organizations

To obtain a list of the various civic organizations in each community, sixty-nine Chambers of Commerce were contacted. One hundred percent replied. Although the Chambers of Commerce were not asked if they would be willing to sponsor meetings or programs on mental retardation, this is a resource which should be utilized in the future campaigns. This is especially true in view of the fact that of the 1,800 organizations suggested by the Chambers of Commerce, only 3% replied to the questionnaire, thereby rendering impossible the making of any conclusions as to their present work in the field of mental retardation.

III. NEWS MEDIA AND PRINTED MATERIALS

A third survey was made to enumerate the various channels for communication concerning mental retardation that are currently being used and those which could be used in the future; to evaluate the effectiveness with which these channels are being used and to suggest ways for better utilization.

A. News Media

Newspapers and radio and television stations constitute the most obvious means of disseminating information to the general public. For this reason, questionnaires were mailed to 174 newspapers, but only 67 (38.5%) replied; to 136 radio stations , of which 80 (59%) replied; and to 17 television stations, receiving eleven (65%) completed forms.

The most significant findings and conclusions from the news media survey are as follows:

(1) 30% of the newspapers do not recall having printed an article on mental retardation within recent months.

(2) At least 21% (probably more) have not printed an article within the last year.

(3) Most requests for programs or articles came from volunteer groups.

(4) There appears to have been little public response in the past to both programs and articles.

(5) The majority of programs or articles appear to be local in origin.

(6) Only 15% of the newspapers are using (have used) the Advertising Council advertisements, whereas 78% of the radio stations and nearly 70% of the television stations with negative responses stated that the Advertising Council materials had not been received.

(7) The tone of some replies suggests that news media personnel would appreciate at least an occasional word of thanks for their help.

(8) The percentage of replies to the newspaper survey was disappointing. The significant factors indicated here may be a lack of knowledge. A number of the respondents who answered "No" to having used a news release or feature story recently commented that their paper did not receive any information concerning the retarded.

(9) Nearly all of the qualified "Yes" answers to the question concerning cooperation in a publicity campaign were related to the word local. Small newspapers do not run national or state news, and apparently want news releases or educational feature articles on mental retardation to have a local connection. The low percentage of the papers which use the Advertising Council materials (distributed nationally) is strong supporting evidence that an article must be of direct local interest.

(10) It seems clear that very few radio and television programs are used. Many respondents qualified their "Yes" answers to the question about recent programs on mental retardation by reporting "spots" or announcements. The replies indicate that various groups such as the Association for Retarded Children, health agencies, or civic organizations request public service plugs or announcements, but few full programs are broadcast. The high percentage of stations using the Advertising Council materials indicate that if short, well-produced programs were available, they would be used.

(11) The most encouraging result is almost total willingness of newspapers, radio stations, and television stations to cooperate in a publicity campaign on mental retardation. A serious effort by the State of Tennessee would receive virtually unanimous support from the news media.

B. Community Health Centers - Findings and Conclusions

The fourteen (14) Tennessee Community Mental Health Centers were sent questionnaires seeking information on the availability of diagnostic and counseling services, printed informational brochures, and referral services at each center. One questionnaire was not delivered; eleven of the thirteen replied. Findings of significance are as follows:

(1) Nine respondents (82%) stated that diagnostic and counseling services were available to the retarded at the center. The two centers which provided only limited services are serving other types of clients and reported that a facility with services for the retarded was located in the same area.

(2) Only three centers replied that they have printed materials available for distribution.

(3) Nearly all centers refer families of retardates to specific persons or facilities (Department of Vocational Rehabilitation, special education classes, institutions or social workers) for further services. However, only three of the centers actually referred families of retardates to a local Association for Retarded Children. This might indicate the need for better coordination of the centers with the local associations or voluntary agencies.

C. State Hospitals

(1) Four replies from the five state mental hospitals were received. Three of the four stated that they provided services for the retarded. Of these: none have available printed materials, two have cooperated with local radio (or television) programming and/or provided speakers for meetings on retardation, and two cooperate with a local volunteer group which aids the retarded.

(2) The work of the two institutions for the retarded (Clover Bottom Hospital and School and Greene Valley Hospital and School) in public relations and information was already known. Staff members from both institutions frequently

participate in community programs dealing with some phase of mental retardation. Both institutions publish newsletters, and both have prepared a set of slides to accompany talks given by staff members. The administration and staff of both institutions are aware of the importance of public understanding of mental retardation.

D. School Superintendents

The following few sentences reveal the pertinent findings of questionnaires sent to the Superintendent of Education in Middle Tennessee. The fact that most of the school systems used some public means of disseminating information concerning their special education programs, the most common means being newspaper, PTA meetings, and personal contact, is commendable, but the overall results of the questionairre are startingly negative. For example, only nine of the thirty-four (34) replies received have available printed materials on mental retardation. Furthermore, the only materials that were specified as being available for distribution by any of these nine affirmative respondents were regular publications which very probably receive only limited distribution among school personnel and not among parents or community groups.

E. Tennessee State Departments and Agencies

(1) All Tennessee Departments either publish a newsletter which is circulated to employees and/or a periodical which receives wider circulation. The replies indicated that (a) the departments would welcome pertinent articles on mental retardation and (b) little use is being made of these channels at present.

(2) The publication of the Department of Mental Health, Mind Over Matter; the newsletters of the state institutions for the retarded; and certain publications in the Division of Vocational Rehabilitation are exceptions to the use of State departmental periodicals for information on mental retardation. One agency volunteered the information that "We have never been asked."

IV. RECOMMENDATIONS

The findings of the task force led to many recommendations available in the original report from the Tennessee Department of Mental Health. In summary form the major recommendations are as follows:

(1) The **SPECIAL ASSISTANT** to the Governor on Mental Retardation, as recommended in the chapter on Coordination and Implementation, should develop a major and continuous public relations and information campaign. This office should:

(a) Be responsible for the dissemination of general information regarding mental retardation.

(b) Employ a public relations director with no other responsibilities.

(c) Make an intensive effort for inter-departmental cooperation and stimulation of broad local participation and cooperation.

(d) Provide information for and obtain utmost cooperation from mass media.

(e) Seek to encourage an ever-increasing flow of information between the various professional groups with whom retardates come in contact.

(2) The office of the Special Assistant or the appropriate State department should provide information for the general public through regular publications (such as those of the Department of Mental Health) and should compile a variety of brochures and pamphlets designed for specific fields, i. e., medicine, social work, law enforcement, etc.

(3) A directory of services for the retarded in Tennessee should be compiled and published immediately and kept up to date.

(4) The Special Assistant to the governor should work closely with the schools, colleges and universities (both public and private) providing information and working toward the inclusion of mental retardation subject matter in professional education and should offer expert assistance in special programs.

(5) All departments of state government should designate one or more staff officers to work with the public relations director in developing the content for brochures, radio and television programs and news releases which affect their departments.

(6) There should be an intensive effort to promote the use of materials on mental retardation in regular publications of professional organizations, volunteer organizations, religious organizations, and state departments and agencies.

(7) The public information program should be a continuous effort with constant reevaluation, revision and follow-up rather than one large campaign in the first year. It must be directed not only to the public generally but specifically to social workers, teachers, physicians, clergymen, attorneys, employers and others not only during their initial education but throughout their professional lives.

It should be clearly understood that the success of every program envisioned by this report hinges upon an awareness and understanding of those programs by the public generally as well as by the personnel of each agency or instrumentality involved in specific programs. There must be a cross-flow of information and ideas if new discoveries are to be made and present knowledge is to be utilized in order to avoid the present high cost of retardation in terms of lost money, lost happiness, lost opportunities, and wasted human resources.

SPECIAL EDUCATION SERVICES

This Chapter Is Based on the Report of the
Problem Study Group in Special Education Services

SPECIAL EDUCATION SERVICES

In any discussion of mental retardation there are three problem areas which should always be discussed conjunctively - education, vocational training and employment. As the President's Panel on Mental Retardation has said "We must seek 'habilitation' rather than 'rehabilitation'." This means there must be early identification and evaluation and then a vocational preparation program closely coordinated with effective special education classes which emphasizes social and vocationally useful skills as well as intellectual skills.

The goal of education and habilitation of retardates is to assist them in attaining as nearly "normal" a life as their potential permits. The National Task Force has recommended, and Tennessee adopts, the principle that "the retarded be recognized as having equal natural rights with the intellectually favored to proportionate educational and habilitation advantages. The satisfaction of these rights must be legally demanded on the basis of social justice and not left to caprice or compassion."

RECOMMENDATIONS

A. Pre-School Services

1.) Emphasis should be given to proposals and recommendations which urge that pre-natal care be available to all mothers, especially those in the "High Risk" group.

2.) Initially, the sixteen Mental Health Centers now in existence in Tennessee should increase their staffs to enable them to provide additional early diagnosis and evaluation services to retardates. Over twenty such new facilities should be established across the state. Each retardate should have available the services of a pediatrician, internist, psychologist, psychiatrist, neurologist, vocational rehabilitation counselor, social worker, public health nurse, and educational specialist. Ultimately, however, the recommendations contained in the chapters on Community Care Centers and on Case Finding offer the best approach to early diagnosis and evaluation needs.

3.) Projects should be undertaken to enrich and stimulate the learning opportunities of pre-school children who live in homes where such opportunities are inadequate. Programs are needed to facilitate adequate development of basic requirements such as language usage and desirable social values in children of depressed circumstances. Another integral part of a good pre-school experience is parent education which is achieved by meetings of groups of parents and educational workers.

RECOMMENDATIONS

B. Expansion and Improvement of Special Education Services

1.) Seventy-five counties in Tennessee had special EMR (educable mentally retarded) classes. Only thirty-six counties had special SMR (severely mentally retarded) classes. Because most surveys indicate there are retarded children throughout the State, it is recommended that every school system should be required to have at least one class, adequately staffed, for every fifteen retardates.

2.) The educational evaluation of mentally retarded individuals should be based upon a more comprehensive diagnosis which would be used as a basis for placement in classes with better planned curricula. In some SMR classes the "curriculum" is little more than baby-sitting and in some EMR classes the curriculum is so watered down as to be of little value.

3.) Students in special education programs should have a well-rounded school program which would stress, however, manual skills rather than academic training. Retardates need more physical education programs and pre-vocational and vocational classes. By having workshops of various types, there is greater opportunity to have the students spend part of their time on class-room work and part on shop work. Time spent in developing employable skills can be gradually increased with age instead of having a sudden transition from classroom to shop as now happens far too frequently.

4.) There should be a written agreement among the state agencies which will be supplying the various services needed by the special education classes guaranteeing a "dove-tailing" of services.

5.) A mandatory class attendance code with legal enforcement for all retardates eligible for school attendance should be more stringently enforced.

6.) A records system to follow retardates from identification through job placement is recommended.

7.) Anytime a retardate cannot be served in his county, mandatory provisions for reciprocal agreements among County Superintendents is advised to insure that all retardates are adequately schooled and trained.

8.) While it is generally agreed that EMR classes should be at the regular public schools, serious consideration should be given to placing the SMR classes at the Community Care Centers along with the sheltered workshops, training centers, and other related services as is now done at the Orange Grove School.

9.) The State Department of Education or university departments of education should establish a mental retardation instructional materials center to insure classroom instruction of retarded children.

RECOMMENDATIONS

C. Personnel Training

1.) Teacher Certification

(a) Teachers for retardates should have to meet special requirements for qualification.

(b) A time limitation for temporary placement should be required of all non-degreed and non-certified teachers and substitutes within these special classes. No teacher shall hold tenure without certification and the salary shall be less than that for certified teachers, with a supplement given only after certification.

2.) Other Professional Personnel

(a) Other personnel working with retardates should have basic "exposure" to the problems of retardation, including training courses and classroom visitation.

(b) Nurses, policemen, probation officers, and others working directly with retardates should have supervised experience included in their training programs (See the Public Awareness chapter for information on the present lack of such training.)

3.) Lay Personnel

(a) Information and training should be made available to such groups as PTA's, churches, Scouts, and other civic organizations.

4.) Administrators

(a) Only certified and experienced personnel should be employed in administrative positions both on the state and local levels.

(b) A full-time supervisor of special education should be employed by local systems. Initially , one person might serve two counties of low population.

5.) Colleges and Universities

(a) Statutory uniformity of college and state requirements for certification is strongly recommended.

(b) A screening committee at each institute of higher learning should be responsible in the choice of personnel to be trained and certified.

(c) A guidance and counseling service should be available throughout the training program of the potential teacher or administrator.

VOCATIONAL TRAINING AND EMPLOYMENT

This Chapter is Based on the Report of

The Problem Study Group of Employment Opportunities for the Mentally Retarded

VOCATIONAL TRAINING AND EMPLOYMENT

Assistance to the mentally retarded in securing employment is one of the most important services that can be rendered to both the retardate and to the nation. The preceding section, in which the need for adequate educational services was discussed, should be considered along with this section because success in the fields of vocational training and employment of retardates depends on there also being appropriate educational opportunities. Beginning in the high school years and continuing afterwards, there must be vocational training geared to the individuals work potential. WITH ADEQUATE EDUCATION, VOCATIONAL TRAINING AND ASSISTANCE IN JOB PLACEMENT, it is estimated that APPROXIMATELY 85% OF ALL RETARDATES HAVE THE POTENTIAL TO FILL JOBS REQUIRING LIMITED SKILLS IN COMPETITIVE EMPLOYMENT. The employment of this group will result in converting individuals who are now the hard core unemployed and the welfare recipients into full-fledged wage earners and taxpayers. The economic value of vocational rehabilitation of the mentally retarded is clearly demonstrable. The Vocational Rehabilitation Administration reports that 92% of the 5,900 retardates rehabilitated in 1963 had no earnings at the time of acceptance and less than 1% earned $40. or more per week. After receiving vocational rehabilitation (evaluation, training, placement and related supportive services) 93% had earnings, with 44% earning $40. or more per week.

In addition to the employable 85% another 10% of the retardates are capable of working in a sheltered environment; while for this group the economic benefits are relatively insignificant, the increase in personal dignity experienced by the retardate is immeasurable.

I. PRESENT OBSTACLES TO EMPLOYMENT AND OCCUPATIONS FOR WHICH RETARDATES CAN BE TRAINED

The major obstacle to employment of retardates has been that employers are either uninformed or misinformed as to the nature of mental retardation and to the fact that retardates can be productive employees. As the public information program envisioned in the Public Awareness report progresses, employers will learn to use the limited skills of retardates and how to supervise them in order to bring out their full potential. At the same time, fellow employees should then at least be more willing to accept them and, hopefully, to assist and encourage them. Another obstacle to employment is automation which by eliminating unskilled jobs throws displaced, capable persons into competition with retardates for those similar, remaining jobs. The solution to this problem is more complex than that of the first obstacle, but technological progress appears to be creating jobs in the new space-age industries which will absorb the fully capable workers. Furthermore, experience has shown that retardates often make the best employees in service industries, a sector of the economy which is presently undergoing substantial expansion. These jobs, such as kitchen workers, bus boys, janitors and yardmen, are preferred by retardates because of their routine and repetitive nature while these same reasons often cause dissatisfaction and high turnover among normal employees. Retardates can also perform adequately the more simple jobs in factories and department stores and do basic construction work.

Parental attitudes also pose problems. A well motivated retardate can be frustrated and confused if his parents scorn the type of work he is capable of doing and willing to do; the rate of pay he can expect to earn, or the environment in which he has found employment. The placement officer will have difficulty placing a retardate even after he has had adequate education and vocational training if the parents fail to understand and cooperate.

II. VOCATIONAL REHABILITATION

A. Evaluation

As pointed out in the chapter on Community Care Centers, there is a need for a sheltered workshop and a vocational training service in every county in Tennessee, except possibly in the sparsely settled rural areas. Before a training program can be planned for any retardate, it is essential that there be an evaluation of his vocational potential. This evaluation will reveal the limits of the individual's ability and determine his occupational classification by considering his mental and physical abilities, personality traits and his social background. However, it must be clearly understood that no evaluation can be considered valid, unless the MR evaluee has been given adequate time (often a week or more) to establish a feeling of security in the new environment, and a rapport with the evaluator, both of which will provide motivation and allow him to demonstrate his maximum potential.

At the completion of the clinical testing period, depending on the findings of these tests, the retardate should be assigned to either the sheltered workshop or the training center where further evaluations will be made.

B. Training

The type of educational and training program in which the retardate is involved has a direct bearing on his subsequent employability. It must be recognized that this is a "special" program and that "normal" educational concepts are inapplicable. The training of a retardate must be pointed toward making him as employable as possible within the range of jobs for which he is suited, not necessarily directed toward a traditional education in the "three R's." For example, numbers should be taught to enable the individual to know when he has placed a certain number of bolts in a package - with little or no regard for the idea that he should understand the conceptual nature of numbers. It must be remembered that education and training are not ends in themselves, but only a means to the end that each retardate will be equipped as best possible to achieve the fullness of life for which he is capable.

1.) Sheltered Workshops. - Following the initial evaluation of the individual's vocational potential, he should be assigned to either a sheltered workshop or a vocational training center. THE FUNCTION OF THESE TWO AGENCIES MUST NOT BE CONFUSED. A sheltered workshop should be intended primarily to provide terminal employment for those whom the evaluation tests have shown cannot function satisfactorily in competitive employment. The sheltered workshop may also serve in a holding capacity for those who require long term habit training before they can be made available to outside industry. A vocational training center, on the other hand, is intended primarily to train for eventual placement in competitive employment. This should not be interpreted to mean that there will be no movement between these two operations as evaluation will continue in both. It may often be desirable for both the workshop and the training center to be housed together under one administrator.

In operation, the sheltered workshop is intended to afford employment for those who cannot, AT THE TIME OF REFERRAL, function satisfactorily, in competitive employment. Careful evaluation, PRIOR TO, NOT AFTER, referral, must be used to provide the criteria for classification as Sheltered Workshop "Employees". The evaluation process should be deliberate and thorough. It should be conducted in both clinical and actual work situations. Thus, an applicant, having received maximum benefits from his Special Education Classes, should be sent to the DVR Counselor who, in turn, arranges with the Evaluation Center for job sampling and other testing. Following a two to three week testing period in the clinical setting, the evaluee is tried out in actual work situations under trained leadership to determine his worker characteristics of concentration, self-control, etc.

If the final report indicates that there is no potential for other than the simpliest jobs AT THIS TIME, then the referral is made to the Sheltered Workshop on a long term or terminal employment basis. Many evaluees may be found to have a work potential buried beneath unacceptable personality characteristics or correctable physical or mental habit limitations. These evaluees are designated for a long range program of work habit training, personality development and work therapy within actual production situations. They are constantly supervised, coached, corrected and properly motivated toward self-improvement. They operate in a special department of the Sheltered Workshop. A specific program is recommended for each individual based on his particular limitations and assets with emphasis on training for ultimate placement in outside employment rather than being in the Sheltered Workshop as an end in itself.

Even those diagnosed as suitable only for terminal work should be periodically re-evaluated every two or three years, or sooner if improvement is noticeable. Concurrent with evaluation, work habit training and personality shaping, weekly placement classes are conducted for all. Here in the company of his peers, the potential employee is taught by precept and example how to find a job for himself. It is, in effect, group psychology applied to the business of getting and holding a job.

A Placement Officer, using the final report of the Evaluation Coordinator acts upon recommendations of specific jobs and types of work for each evaluee-trainee at the completion of his pre-employment program. Once placed, follow-up on a schedule of counseling the worker and conferring with the employer anticipates and hopefully prevents problems of job adjustment and promotes mutual acceptance.

The above described program functions within the Memphis Goodwill Industries and is applicable to the larger Sheltered Workshops that are developing in metropolitan areas.

Under most circumstances the sheltered workshop is intended to provide full-time employment at simple tasks at less than full rates of pay. Contract work is normally performed for local industries on a per piece basis. Production of simple articles for direct sale may also be undertaken. In addition to a relatively small paycheck, the participants are kept busy in a congenial atmosphere, receive training in social as well as manual skills, and have the satisfaction of being productive.

Although a sheltered workshop may be designed primarily for the retarded, there are advantages to including other handicapped persons in the program. Those who are physically handicapped but mentally normal can perform tasks that cannot be performed by the mentally retarded, particularly administrative ones. The range of job contracts that can be fulfilled is widened, thereby giving the retarded greater job variety. Presence of the physically handicapped also widens the social experiences of the retarded and can also be expected to broaden the program's community support. However, it cannot be over-emphasized that such combined workshops must not be allowed to gravitate toward serving the physically retarded at the expense of the mentally retarded.

Other problems which now limit the workshop system in Tennessee, presently numbering ten centers, are:

(1) Limits established for eligibility on the basis of mental retardation, that is, the 50-60 IQ spread exclude feasible cases.

(2) Some workshop management has not yet developed to the full level of competence needed to offer the retardate the wide spectrum of training and counseling he requires.

(3) Some workshops provide no training for specific jobs available in the labor market. It seems to be assumed that the retardate will make a "transfer of learning" from the workshop skill to the skill required in full time employment, but this may not occur.

(4) The Division of Vocational Rehabilitation Counselor, without additional training or reduction of his other duties, is expected to handle the caseload in the center in its area in addition to his regular caseload.

(5) There is an insufficient use of the workshops as a means of providing terminal placement of retardates unqualified for employment elsewhere.

2.) Vocational Training Centers. - Vocational training as used in this report is primarily preparation for placement in competitive employment. It includes emphasis on three major objectives: (1) occupational training, (2) work adjustment training, and (3) personal adequacy training. OCCUPATIONAL TRAINING usually involves contract work obtained from local industries and is intended not so much to produce shop income and pay for the trainee as to provide work experience that will enable the trainee to fit himself into local employment opportunities. The exclusive use of contract work is of limited value. An analysis of the kind of contract work available (especially in non-industrial communities) reveals that such work is usually a "nuisance job" the employer is glad to remove from his production line. He rarely accepts a diagnosed retardate in the factory environment and virtually never in the production line. Therefore, such "occupational training" is not used as such. Emphasis should be placed on producing quality work in service type jobs - a truly good clean-up man; an efficient, careful, reliable dishwasher, shoeshiner, parking lot attendant, etc. This requires specific training as a clean-up man, as a dishwasher, as a shoeshiner, etc. Work adjustment training is intended to teach the trainee to get along with his supervisor and co-workers and to put in a full day's work for a full day's pay. Personal adequacy training primarily teaches the trainee to dress and act properly. The total training situation should simulate the genuine work situation as closely as possible so that the change will not be too abrupt when the trainee does enter the field of competitive employment.

After a four to six week period, many trainees are ready for vocational placement as their vocational aptitudes have been ascertained, their work abilities evaluated, and their vocational training completed. But there are other individuals who for some reason - e.g. are deeply withdrawn, need to learn perseverance, need to learn how to respond properly to directions -- need to be held for long-term work-habit development in a program tailored especially to correct their problems. There is substantial rehabilitative influence in the element of time. Training centers should not hesitate to keep individuals needing long-term training because retardates can be brought up to a point and if time does not allow for them to be retained within an environment related to that for which they are being prepared, they retrogress rapidly when returned to community life.

3.) Residential Facilities. - Residential facilities are needed at the sheltered workshops and training centers for those individuals who have no homes or cannot commute daily. Most would be encouraged to return home on week-ends to maintain contacts with their parents and families and to obtain needed comfort and advice. Also needed are "half-way houses" which would be a similar unit but derive their name from the nature of the role they would play -- a stop half-way between the residential facilities and a normal home. These "houses" could provide further training in being independent yet would have recognizable ties to the residential facilities so as not to sever the trainee's sense of security too abruptly. The lack of domicillary arrangements is a serious handicap in the utilization of the services already available and their development must coincide with the construction of training centers if maximum benefits are to be realized from the latter.

C. Placement and Follow-Up

When the retardate is ready for competitive employment, whether after four to six weeks of training or after long-term work habit development, his prospects for securing a job are improved if there is a placement service operated by the evaluation and training center. Special job opportunity analysis, placement techniques, and follow-through are required for this handicapped group and should be provided by the Division of Vocational Rehabilitation. Most of a placement service's work involves negotiating with employers to arrange longer learning periods and increased instructions for the retardate and for follow-up privileges for placement service employees. The follow-up contacts with the placed worker must not be so frequent as to become a nuisance to the employer, yet they must be often enough to insure that the retardate has assistance in settling down to his job.

Recent experiments and practice indicate that some retardates are capable of placing themselves. This should be encouraged when appropriate; with these individuals being taught the proper techniques of job finding, as a part of their training process.

III. INTERAGENCY SPONSORSHIP

Under the plan envisioned in the chapter on Coordination and Implementation, various state departments will be involved in the operation of these vocational training centers. It is, therefore, imperative that the role of each department be clearly delineated, responsibilities assigned, and channels of communication established in order that the centers might operate efficiently and harmoniously. A few general thoughts on the roles of some state departments are as follows:

(1) The Department of Education would provide for the educational and occupational training through the Division of Vocational Education and Division of Vocational Rehabilitation.

(2) The Department of Public Welfare would provide those services consistent with its operations since many retardates are on welfare roles.

(3) The Department of Public Health would provide health services for the centers.

(4) The Department of Mental Health would provide psychological and psychiatric personnel.

(5) The Department of Employment Security would be responsible for securing employment opportunities.

(6) The Personnel Department and all other state agencies need to develop an appreciation for the work retardates can do and by the hiring of them set an

example for private industries.

This well illustrates the need for a special high-level coordinator for the retarded as discussed in the chapter on Coordination and Implementation.

IV. CONCLUSIONS AND RECOMMENDATIONS

Our society has not yet decided to make the degree of social and economic investment which will have a significant impact upon the training needs of the mentally retarded. Until this decision is made, many retardates will have to endure the loss of dignity, isolation from society, and the other by-products of long-term idleness throughout most of their working lives.

This is presently true even though experience shows that with the proper training 85% of the retarded can qualify for productive work in a large number of competitive occupations. To prepare these individuals for the world of work and a fuller life in Tennessee, the following major recommendations are made:

1.) A Special Assistant to the Governor should be appointed with authority to coordinate the activities of the various divisions of the state government.

2.) The educational and training objectives of special education should be reviewed with the primary motives being pointed to the development of (a) occupational adequacy, (b) social competence consistent with the work level a retardate will assume, and (c) personal adequacy.

3.) Legislation should be enacted to provide pre-school or preparatory classes for retardates.

4.) Area diagnostic centers should be developed or existing community mental health centers should be expanded to service families of the retarded. This is important because at present the family of the disadvantaged individual is usually the forgotten and neglected problem.

Only when the counselor or instructor achieves parental cooperation does the retardate make the occupational plan whole-heartedly his own, with a feeling of security - only then is he "able and willing to accept employment suitable to his ability."

5.) Adequate work - school experiences should be provided for youngsters as they move into the working age.

6.) The training centers now being established across the state should be developed into Comprehensive Work Evaluation and Training Centers incorporating a well-planned job placement and follow-up program. These centers should expand their programs to handle also the more severely retarded.

7.) Once a person is served by the Division of Vocational Rehabilitation, his case should not be closed a "rehabilitated" until at least six months in employment have passed rather than the present two months. The regulations should also be altered to make further services to a client readily available as he needs them.

8.) The state should provide assistance in developing more sheltered workshops in connection with the work training centers.

COMMUNITY CARE CENTERS

This Chapter is Based on the Report of
The Problem Study Group on Community Care Centers

COMMUNITY CARE CENTERS

Throughout the nation there has been a growing awareness of the need to keep the retarded in the community insofar as this is possible. Institutional care is not the answer for several reasons. First, institutions are full to overflowing despite unparalleled construction of new facilities. Clover Bottom Hospital and School of Donelson, Tennessee, houses some 1,400 patients and has a waiting list of a third this number. Recent construction of Greene Valley Hospital and School near Greeneville, Tennessee, with a present 900 bed capacity, has not relieved the situation and already has a waiting list itself approximately equal to its capacity. Planned construction of a state institution at Memphis with a capacity of 1,400 will only relieve the pressure temporarily. Secondly, institutional care is expensive and is growing more so. Original construction now costs in the order of $12,000 to $15,000 per bed. Operating costs have risen from about $2.50 per patient per day at Clover Bottom in 1959 to a present average cost of about $5.00. Total cost now averages about $14.00 a day. Operating costs alone are far more expensive to the taxpayer than care in the community. Thirdly, institutional care is not the answer as far as patient welfare is concerned, except in relatively few cases. This is true because institutions generally do not contribute to the development of the retarded and it has now become clear that with proper education and training approximately 85% of all retardates can hold jobs and become reasonably responsible citizens. Furthermore, it is in the community that the educated and trained retardates will find jobs. Because of these considerations, strenuous efforts must be made to reserve beds in the state institutions for only the most extreme cases of retardation. All others should, insofar as possible, be kept in the community. Community programs and facilities must be developed to provide retardates with the diagnosis, care, education, training and job placement that are required to help them become productive members of society.

I. COMMUNITY SERVICES FOR THE RETARDED

A community care center may be simply a building or a group of buildings housing a variety of coordinated services (evaluation, care, education, training, job placement) for retardates of the community; or it may be a central building housing most of the services with other services housed elsewhere in the community but with all services coordinated by a single community organization. If the retarded are to be productive members of the community, this wide variety of services and facilities must be provided.

It is recognized, as a practical matter, that it is most unlikely that Tennessee communities will, in the immediate future, be able to provide the full array of services recommended. Nevertheless, it is a goal toward which energies should be directed. Obviously, it would be impractical to attempt to organize all of these services in the less populous counties, but they could be made available from regional centers and most could be obtained from centers organized by several adjacent counties.

A. Regional Services

Six regional centers should be organized to provide a complete array of services for the retarded of these areas and to provide supplementary services for the smaller surrounding counties. These six centers should be in conjunction with major universities in order to facilitate research projects and to take advantage of the specialists needed on a part-time basis. The locations which appear most appropriate are:

1.) Memphis (built around UT Medical School and Child Development Clinic).
2.) Jackson
3.) Nashville (built around Vanderbilt University and Peabody College).
4.) Chattanooga (built around Orange Grove School and University of Chattanooga).
5.) Knoxville (built around University of Tennessee and UT Hospital).
6.) Johnson City (built around East Tennessee State University).

All of these cities have major universities except Jackson, but a center is necessary there to give a good distribution across the state. The six counties in which these cities are located include 46% of the state's population. The major services which should be provided by all six of these regional centers are described briefly in the following paragraphs:

1.) Comprehensive Diagnostic Services. Whether a retardate can stay in the community or must have institutional care, the type of training and education he can assimilate, the probability that he can become partially or wholly self-sufficient, and the counseling that must be given his parents are all dependent upon the quality of the diagnosis. Yet diagnosis is the weakest link in the chain of services in Tennessee as only the Child Development Clinic in Memphis now performs a comprehensive diagnosis. The services of this one clinic are limited by its geographical location and lack of funds.

Diagnosis requires from a week to six weeks with the child in residence throughout this time and with the parents present at least on the first day to provide background information and on the last day to receive instructions and training. Diagnosis must be repeated at intervals to check on progress and changes. As the child approaches physical maturity, evaluation replaces or supplements diagnosis in that the goal is then to determine the kinds of work in which he is most likely to succeed so that his education and training can be programmed accordingly. While partial diagnosis or screening may be carried out in the smaller community centers, only the regional centers can be expected to have the array of specialists needed for comprehensive diagnosis. For the type of "interdisciplinary" diagnosis needed, see "Case Finding and Comprehensive Diagnosis", Section IV.

2.) Pre-School Classes. Starting at about age three, these classes are needed to help retardates, particularly those from low-income families, to develop basic self-help skills, to provide socialization and group training, and to teach pre-academic skills, particularly language development. This training may be continued beyond age six, perhaps to age eight or ten, for some of the retarded to enable them to develop the habits and skills needed before entering the special education classes.

3.) Special Education Classes. This subject will receive only brief mention here because the chapter on Special Education Services deals with it fully. While these classes have existed in a few Tennessee communities since about 1953, they are still not available in many counties. Yet these classes are the backbone of community programs for the retarded. The regional centers and community centers herein proposed should be equipped to accept children from surrounding counties with populations too small to warrant these classes on a county basis.

There is a need to re-examine the present arrangement of having only EMR (educable mentally retarded) and SMR (severely mentally retarded) classes. Perhaps the classes, at least at the regional centers where there are sufficient students, should be organized for three or even four levels of retardation. This would be possible in the regional centers where the number in the special classes is sufficient to warrant more than two levels. Furthermore, perhaps the SMR classes, rather than being part of the local school system, should be operated by a separate corporation at the community care center along with the sheltered workshop, training center, and other services.

4.) Day-Care Services. Some of those enrolled in the pre-school classes will not graduate to the special education classes because of limited mental ability or other factors. If they remain at home, this imposes on the parents a tremendous burden which may become unbearable eventually. The primary objective of day-care services is to lighten the burden on parents so they can care for the retarded child in the home. Day care can also assist in developing basic skills such as dressing, eating, toilet habits, and personal grooming. It can also help the child to improve his language development and train him to get along with others. As these developments occur and as evaluation continues he may be able to move into an SMR class or sheltered workshop; in any case, he will learn simple craftwork to help keep him occupied. Each regional center should be staffed with sufficient social workers to provide close contact with the parents to insure that personal skills developed are carried home.

5.) Sheltered Workshop Services. Initially it should be pointed out that the subject of sheltered workshops is fully discussed in "Vocational Training and Employment", Section II B1. Nevertheless, the importance of this subject calls for brief mention of it here also. A sheltered workshop is intended to afford terminal employment for those who cannot function satisfactorily in competitive employment. It may be thought of as a service between that provided by day care and training for competitive employment. Undoubtedly, there will be movements between day care and sheltered workshop and between day care and sheltered workshop and between sheltered workshop and training center. There may also be movement between the sheltered workshop and special education classes at both the SMR and EMR levels. In many instances a sheltered workshop may be considered an adjunct to these classes with pupils spending a portion of each day in the sheltered workshop. The need for these various movements point up the need for housing these coordinated services in one building if at all possible. Sheltered workshops in regional centers or large population areas can serve both the metropolitan area and adjoining counties which have populations so small that transportation to the regional center is more practical than organizing small workshop programs. As previously noted these sheltered workshops may have comprehensive programs, and serve as both workshops and vocational training centers.

6.) Vocational Training Services. While this topic is also discussed at length in Section II B2 of "Vocational Training and Employment", it also merits some discussion here. Vocational training is preparation for placement in competitive employment. It includes emphasis on work evaluation, work adjustment training, occupational training, job placement, and whatever follow-up is necessary to assure success on the job. As noted previously, there will undoubtedly be movement between the training center, sheltered workshop, and special education classes. The regional training centers may also serve adjoining counties which have populations too small to warrant their own. The vocational training services must be coordinated closely with the Tennessee Division of Vocational Rehabilitation using the DVR counselors to the maximum and providing contract training for clients of the counselors to the extent feasible.

7.) Recreational Services. Recreation is more essential for the retarded than for the normal person because retardates are not able to enjoy many of the other activities normal persons participate in during spare hours. But even more important are the consequencies of the inactivity of the retardate who is not kept active. An unreasonably high percentage of retardates suffer from problems of poor muscular development, inadequate coordination, obeisity, frustration and stress simply because they have not been encouraged to keep as active as possible and often are involved in no pleasurable experience other than eating and self-stimulation (e.g., thumb-sucking, masturbation).

Recreational activities should be provided by the regional centers with programs geared to the range of interests and abilities of all degrees of retardation and all ages. Particular attention should be given to teen-agers and young adults to help them develop acceptable social habits. Recreational facilities the regional centers should include are an indoor and outdoor swimming pool, a gymnasium, and a playground. A recreational director and small staff are almost essential. Experience has shown that recreation is an area in which some retardates can excel and practically all can obtain the social skills they so often lack.

8.) Long-Term Residence. Residential care on a long-term basis should be provided by each regional center to serve the following: (a) Graduates of the vocational training program who are holding permanent jobs in the community. This would include those whose parents are no longer living or able to care for the retardate and those from surrounding areas who cannot commute daily. (b) Participants in the regional center programs who have no homes or cannot commute.

9.) Short-Term Residence. To serve the following purposes residential care on a short-term basis should be provided. (a) Children brought for diagnosis would normally stay a week or more. Their parents would also stay a few nights to obtain training and instructions. (b) Special training such as toilet and feeding training, can be provided by regional centers that cannot be done by smaller centers because of lack of staff or facilities. (c) Short-term care while one or both parents is incapicated or when the family desires to take a much needed vacation can also be a highly beneficial service. (d) Those brought to the center for evaluation similar to the type developed by Goodwill Industries of Memphis would need to stay several weeks.

10.) Staff Training. Having the regional centers associated with universities will enable specialists teaching or studying there to obtain practical experience as part of their training. In addition, the regional centers can provide practical training and experience for those who will serve the community centers as workshop supervisors, supervisors of day-care centers, and as helpers in all types of community programs. Even so, it is unlikely that there will be enough trained personnel to serve all community centers. Regional centers will, however, supply additional training as circumstances permit. Seminars and in-service training provided by the regional centers will also permit the community centers' staffs to keep abreast of new developments.

11.) Research and Demonstration. With most of the regional centers closely associated with medical schools and universities and with most of the regional centers providing a complete array of services for the retarded, an ideal situation is present for research and demonstration activities. There is a great need not only for medical research but also for research into teaching methods, school curricula and vocational training methods. With the large sums expected to be available in the form of federal grants, the regional centers should be able to conduct extensive research and demonstration projects. By having these projects conducted in close association with retardates, the work should tend to remain practical rather than theoretical.

12.) Traveling Team Services. The small community centers can obtain supplementary services from the regional centers either by sending their patients with special problems to the regional centers or by teams of consultants from the regional centers making regular trips to the small centers. The latter would be more economical and would also allow supervision of the operation of the small centers.

13.) Services for Parents. Counseling with the parents of a newly discovered retardate is one of the most important services a center can perform. Timely and expert counseling is needed to get parents to accept the fact that their child is retarded and to prevent them from taking the child to one specialist after another at a great expense. As the child progresses by reason of the care center services, frequent consulation is essential if the home training is to complement that provided by the center.

14.) Miscellaneous Services. A variety of other services can be expected to develop within and around the centers as needs are recognized and met. For example, a guardianship program may be necessary for those whose earnings exceed their expenses. Scouting programs might be conducted as part of the recreational programs.

B. Metropolitan Services

In addition to the four major metropolitan areas for which regional centers are proposed, there are several smaller metropolitan areas which need community centers that provide most of the above services. Sullivan and Anderson counties already fall in this class, and others such as Hamblen, Roane and Blount are growing rapidly and will soon warrant full service centers. Also, Oak Ridge, Kingsport and Bristol are populated sufficiently to need a center providing a full array of services. These centers would not, however, provide comprehensive diagnostic services, staff training, major research and demonstration projects, or send traveling staffs to the smaller centers. The Daniel Arthur Rehabilitation Center at Oak Ridge (Anderson County) already furnishes many services for the retarded and other handicapped and could be expanded into the type center envisioned.

C. Communities of Medium Size

A number of cities and counties have populations sufficient to need and support rather complete centers as indicated by the following tabulation of 1960 population.

County	Population	City	Population
Blount	56,525	Maryville	10,348
		Alcoa	6,395

County	Population	City	Population
Montgomery	55,645	Clarksville	22,021
Rutherford	52,368	Murfreesboro	18,991
Gibson	44,699	Trenton	4,225
		Humbolt	8,482
Maury	41,699	Columbia	17,624
Carter	41,578	Elizabethton	10,896
Roane	39,133	Kingston	2,010
		Harriman	5.931
		Rockwood	5,345
Bradley	38,324	Cleveland	16,196
Sumner	36,217	Gallatin	7,901
McMinn	33,662	Athens	12,103
Hamblen	33,902	Morristown	21,267
Hawkins	30,468	Rogersville	3,131
Dyer	29,537	Dyersburg	12,499
Putnam	29,236	Cookeville	7,805
Coffee	28,603	Tullahoma	12,242
Tipton	28,564	Covington	5,298
Lawrence	28,049	Lawrenceburg	8,042
Campbell	27,936	LaFollette	6,204
Wilson	27,668	Lebanon	10,512
Robertson	27,335	Springfield	9,221

With the above twenty counties, all of which have populations in excess of 27,000, and the other cities in the State that have populations over 10,000, there should be about twenty-five community centers in addition to the one or more regional and metropolitan centers. There should be about 300 retardates in a community of 10,000 assuming the retarded to be 3% of the population - a sufficient number to warrant rather complete centers. These community centers would provide both SMR and EMR classes, day-care services, recreational services, sheltered workshop services, vocational training services, and short-term residential services.

D. Small Rural Communities

After all the above had been done, there would still remain some 40 to 50 counties with populations too small and scattered to warrant even the reduced array of services proposed for the centers in the medium-size communities. These areas should also have small centers even though they be little more than a central point of information and coordination. At the beginning, a Public Health Nurse, a Welfare Department worker, or a special education teacher might serve as the contact for all the retardates in the county. This person would arrange for retardates to visit regional centers or for a traveling team to visit them. As community interest quickens, a simple facility providing day-care, a sheltered work-shop and vocational training could be built. In the more densely populated rural counties, a rather complete center might be organized adjacent to the local school with the full use made of the school transportation services. Depending on population distribution and transportation routes, two or more counties might cooperate to create a simple center. Furthermore, in planning community centers in sparsely populated areas, consideration should be given to developing sources and a single facility for all handicapped rather than just for the retarded.

II. COMMUNITY FACILITIES FOR THE RETARDED

The discussion up to this point has been concerned primarily with community services for the retarded without too much attention to the physical-facilities needed to house these services. The plan prescribed for services envisions a complete array of services in six large regional centers, slightly less complete service in some 25 smaller community centers , and less complete services in the 40 to 50 remaining small rural counties of the state, all tied together by means of specialized services in the regional centers for those who cannot be served properly by the local centers. This plan also envisions a single building or closely associated group of buildings at each regional center and community center, insofar as practical to house these services. As the chapter on Residential Facilities makes clear, physical facilities must be planned ahead to best accomodate the full range of programs envisioned.

Coordination of services for the retarded continues to be a major problem at the national, state and local level. Coordination at the national and state levels is obtained largely through organizational structure. At the local level, the committee firmly believes that full coordination can be obtained best by the organizational structure discussed in a following section and by housing the various services in a single building or a closely associated group of buildings. It may not be desirable to house a few of the community services for the retarded in a central facility, particularly when a different pattern has been established in the community and is now functioning satisfactorily. For example, the EMR classes throughout all or most of Tennessee are now housed in local school buildings and operated by the local Board of Education. Some contend that these children could be served better if these classes were physically separated from the regular school classes but the preponderance of opinion is that it may be preferable for EMR children to continue to be in EMR classes at regular school facilities so they will be associated closely with the normal children who are likely to be their future employers.

On the other hand, by placing the EMR classes in a community center where vocational training services are available, it is much more likely that the EMR pupils will be able to spend more of their time learning manual skills as they grow up through the special classes. This would reduce the high dropout rate of the older children in the EMR classes and avoid the abrupt shift from an EMR class to a vocational training center. In Knoxville, the Van Gilder Occupational Training Center located in the Moses School provides this kind of service. In constructing physical facilities for housing community centers for the retarded, serious consideration should be given to housing the EMR classes in the same or closely associated buildings.

The SMR classes should, with little debate, be housed in the community center. Most, if not all, the SMR pupils are sufficiently different from normal children so that they participate to only a small extent in normal school functions and gain relatively little from close association with normal children in school. Their manual skills can be developed to some degree in the sheltered workshop and vocational training center and there should be an opportunity for them to spend increasing amounts of time in these facilities as they mature rather than shift abruptly.

Should the community centers be constructed to house services for all handicapped or just for the retarded? The answer to this often debated question depends primarily on the size of the community . The regional centers should be almost exclusively for the retarded although the sheltered workshops and vocational training centers should also be open to those with other handicaps. Centers in the medium-size communities should probably follow the same pattern, but it appears more desirable in the small communities to construct a center for all handicapped. A center in large or medium-size communities catering to those with all handicaps would undoubtedly tend to dilute the services for the retarded. On the other hand, the number of retarded in the smaller communities is not likely to be sufficient to warrant a full range of services for the retarded alone.

Now that Federal funds are becoming available to cover a major portion of the cost of such facilities, each community should give serious thought to constructing a new building or group of buildings to house all or most community services for the retarded. No longer should the retarded be considered as second-class citizens to be housed in school buildings rated unsuitable for use by normal children. The State should retain an architect to work with each local community in planning its community center and should make no funds available until the plans have been approved by the architect.

To insure that the community center is not out of date soon after completion and to provide for future expansion, the following matters should be kept in mind. First, the site must be selected with care by experts in this field working with the State architect. Transportation for the retarded should be a controlling factor in selecting a site for the community center for the retarded. It must be easily reached from all parts of the community. Second, the site must be of sufficient size to allow for expansion to at least triple present needs. Third, facilities should be designed to keep original cost and maintenance to a minimum, to provide flexibility in the use of rooms as programs change and as the number of participants increases, to permit expansion of the facilities, and to enable the facilities to house the services planned in the most efficient manner. Most facilities should be one-story masonry construction with non-bearing partitions that can be shifted as the need arises. And fourth, recreational facilities should receive careful thought and in the larger communities would include a gymnasium with indoor swimming pool, outdoor pool , and fully equipped playgrounds.

Because services will vary considerably among the regional centers, centers in the medium size communities, and centers in the small rural communities, the facilities needed will also vary sufficiently to warrant a brief discussion of each.

A. Regional Facilities

The six locations recommended for regional facilities are Memphis, Jackson, Nashville, Chattanooga, Knoxville and Johnson City. Each of these regional centers should, with certain exceptions, be housed in a single building or closely associated group of buildings. The EMR classes should be excepted (at least in the four metropolitan areas) because of their large number and because most are now adequately housed in school buildings scattered throughout these metropolitan areas.

In Knoxville, it seems highly desirable for the regional center to be located close to the University of Tennessee, perhaps beside the University Hospital. In Memphis, a site adjacent to the University of Tennessee Medical School would have considerable merit as would a site in Nashville adjacent to Vanderbilt University and a site at Johnson City on the campus of East Tennessee State University. In Chattanooga, because the abandoned school that still forms the nucleus of the Orange Grove School is antiquated, a new building at a new site adjacent to the University of Chattanooga may be a better investment than expansion of the existing obsolete facilities. In Memphis and Nashville, with their large populations, consideration might be given to satellite centers that would reduce transportation problems by providing limited services for outlying areas but with a full array of services only in the regional center.

It should be emphasized again that each regional center is envisioned as providing a full array of services for the retarded of the community plus specialized services for the surrounding region. The regional facility will, therefore, be a large and complex building or group of buildings. Those in the four metropolitan areas can be expected to cost several million dollars. They must be located and planned with greatest possible care and with full attention to each of the many services for the retarded to be housed therein.

B. Metropolitan Facilities

The three metropolitan service centers proposed at Oak Ridge, Kingsport and Bristol and those in other growing population centers would provide a full array of services like those at the six regional centers except that diagnostic services would not be included nor would specialized services for a region. Each might, however, accept children from the surrounding area to the extent that transportation permits.

Like the regional centers, all services for the retarded would be housed in a single building or closely associated group of buildings except that the EMR classes should remain in the public schools. These buildings would be much smaller than those for the regional centers because the population to be served is much smaller, diagnostic services and specialized services for the region are not included, and there would be less opportunity for research and demonstration. The same care should be exercised, however, in selecting sites and designing the buildings to meet present and future needs. At Oak Ridge the Daniel Arthur Rehabilitation Center and the adjoining building housing the SMR classes could be expanded to include the additional services contemplated, but new structures would probably be needed at Kingsport and Bristol.

C. Facilities in Medium-Size Communities

In the 25 communities in Tennessee with populations over 10,000 but below that of the nine or more communities in which regional or metropolitan centers are proposed, a single building should be constructed to house all services for the retarded except, possibly, the EMR classes. Consideration might be given to including the EMR classes in the center, especially if these classes are not well-situated at the present time.

D. Facilities in Small Communities

The forty to fifty still smaller community centers in the state should each have a small building , to house all services for the retarded. As noted in the discussion of community services, these centers may well house all community programs for the handicapped as well as both the EMR and SMR classes. Guidance by the state architect is essential to make sure that proper sites are selected and that the buildings are designed for both present and future needs.

III . ADMINISTRATION OF COMMUNITY CARE CENTERS

Up to this point the discussion has been concerned primarily with the broad array of community services that should be provided for the retarded and the physical facilities needed to house these services. Equally important are the means by which these services and facilities will be administered to best serve the needs of the retarded. Administration of the community services and facilities is a two-fold problem. First, is the problem of coordinating the existing and proposed services to avoid overlaps and gaps, and second is the problem of implementing the recommendations for new and expanded services and facilities made in this report. These problems at the community level are similar to those at the state level studied by the Committee on Coordination and Implementation of Programming for the Mentally Retarded. That committee, after considering various alternatives, recommended that a Special Assistant to the Governor be appointed to work solely for the mentally retarded in much the same manner as President Kennedy appointed Dr. Stafford Warren to serve as his Special Assistant on Mental Retardation.

A. Decentralized Administration

At the community level in Tennessee, services and facilities for the retarded are administered generally in a decentralized manner by various organizations with little or no coordination between services. This decentralization is typified by the following examples.

The local school systems generally administer the SMR and EMR classes with financial support and guidance from the State Department of Education. The Division of Vocational Rehabilitation of the Tennessee Department of Education administers, as of August 1, 1965, ten vocational training centers from its headquarters in Nashville in accordance with legislation adopted by the 1965 General Assembly, but with the assistance of the local boards formed previously. Counseling and job placement of the retarded are also administered by DVR in Nashville through regional and local offices. The Department of Public Welfare and the Department of Public Health in Nashville serve the retarded through local offices. The local Associations for the retarded provide a variety of local services for the retarded, often with the assistance of local civic groups. For example, the Chattanooga ARC has administered a large residential summer camp for a number of years and the Carter County ARC recently started a residential summer camp. Local civic organizations provide a variety of services. In Knoxville, the Sertoma Club operates a preparatory school for children not ready to enter the SMR classes. In Memphis the Duration Club operates a similar school and Little City provides institutional care and schooling. Goodwill Industries, a non-profit organization, provides evaluation, training, and jobs for the retarded and other handicapped in various cities.

B. Centralized Administration - Chattanooga

By contrast, most of the services in Chattanooga are administered by a single organization, the Orange Grove School for Retarded Children, Inc. This corporation is governed by a Board of Directors composed of sixteen members: four elected by the Board, six by the local Association for Retarded Children, three by the local Junior Chamber of Commerce, and the remaining three jointly by the ARC and Jaycees. The Board employs a Director who administers the services and facilities under the Board's direction.

Any examination of the services and facilities for the retarded in Chattanooga as compared with those of all other cities of the state clearly shows Chattanooga to be far ahead of other cities. For example, statistics distributed recently by the Department of Mental Health show the following number of pupils enrolled in the EMR and SMR classes of the metropolitan counties of Tennessee:

NUMBER ENROLLED - Population - ENROLLED PER 100,000

	EMR	SMR	1960 Census	EMR	SMR
Shelby(Memphis)	1,151	173	627,019	185	28
Davidson (Nashville)	1,163	126	399,743	292	32
Hamilton (Chattanooga)	954	147	237,905	402	62
Knox (Knoxville)	759	130	250,523	300	52

The number enrolled in both the EMR and SMR classes of Hamilton County, in proportion to population, is well above that of the other metropolitan counties. Although the Orange Grove School administers the SMR classes and the city and county administer the EMR classes, the high EMR enrollment suggests that the attention and publicity given the retarded by the Orange Grove School has developed a community interest in the retarded that has resulted in more EMR classes and greater enrollment than in any other metropolitan county.

In addition to the SMR classes, the Orange Grove School provides other services and facilities for the retarded, such as: a special class for profoundly retarded that is teaching these extremely handicapped children to do things never before considered possible, sheltered workshop and vocational training services that are the envy of the entire state, residential facility for adult retardates from Clover Bottom Home most of whom now have jobs in the community, and a summer residential camp attended by retarded from all over the state.

Not only are more services provided for more retarded in Chattanooga than in any other metropolitan area of Tennessee, but the quality of the services is higher in the opinion of those who have compared these services.

Why are there more and better services for the retarded in Chattanooga and Hamilton County than in the other metropolitan areas of Tennessee? The committee believes Chattanooga's success can be attributed almost solely to administration by a single Board of Directors through a highly qualified Director. The Board is composed of local citizens interested in the retarded who are willing to devote a good share of their time to developing and supporting programs for the retarded and only the retarded. They have had to obtain funds from every possible source and in this process have obtained the interest and support of the people of Chattanooga. A qualified Director has been able to administer the services efficiently and to study proposed new services objectively. Transportation, always a problem in providing services for the retarded, has been simplified both by a single administration and by concentrating the services at one location, the Orange Grove School. And finally, the people of the area, through the local Board of Directors, have been able to feel that they are a part of the program.

C. Local Administration

The proposed community care centers should be administered by a local non-profit corporation organized for this purpose. This corporation would have a Board of Directors composed of interested local citizens which would employ a Director to administer the services. The corporation should preferably own the facilities outright. If this is not legally possible or financially practical, in some instances, the corporation should lease the facilities for a nominal sum and be responsible for operation and maintenance.

The alternative to this centralized local administration would be a facility owned by local or state government but with services administered by a series of state and local organizations -- a continuation, for all practical purposes of the unsatisfactory arrangements now prevailing in most communities of Tennessee. Operation would be less efficient, there might be rivalry between organizations like that now existing, and there would be no one organization and, more important, no one person responsible for promoting the entire program and for developing new and expanded services. A coordinating committee would be of some service, but experience has shown that it is almost impossible to coordinate the efforts of organizations that are completely independent.

The local non-profit corporation is believed to be the best administrative device, not only for the regional and metropolitan centers, but also for the more modest community care centers in the medium size and small rural communities. In fact, this device is apt to be even more successful in the small communities than in the metropolitan areas. Administration by a local Board of Directors will give each center considerable freedom to adjust its operation to local conditions without too much autocratic control by the various agencies.

D. State Regulation

Although the proposed community care centers will be administered by a local Board of Directors through a staff headed by a Director; it is essential, of course, that the facilities and individual services be regulated and standardized to a degree by the appropriate state agencies. This will occur through state licensing laws and through the controls attached to State and Federal funds involved in constructing the facilities and providing the services. Day care centers, for example, must be licensed by the Department of Public Welfare. The SMR classes will be financed largely , as at present, by state funds provided by the Department of Education, and the rules and regulations of the Department can be expected to follow these funds. Similarly, the vocational training centers, sheltered workshops, and other services for the retarded will be subject to standards and controls set by the state agencies from which financial assistance is received.

Thus, under the proposed plan the community care centers will operate under local control with opportunity for the use of local initiative and drive but will be subject to standardization and control by the appropriate state agencies. Appointment of a Special Assistant to the Governor who will serve as chairman of an Interagency Committee as recommended by another study committee, will provide for coordination of these standards at the state level and will prevent the community care centers from being subject to unreasonable and possibly conflicting state standards.

IV. IMPLEMENTATION OF PLANS FOR COMMUNITY CARE CENTERS

The community care centers visualized in this report cannot be developed throughout the state at the same time nor can they be developed overnight. It will take time to create the local nonprofit corporations that will administer the community care centers, to work out locally what existing services for the retarded will be brought into the community care centers, what new services will be added, and how these services and facilities will be financed.

The local ARC's should take the initial step of calling together representatives of the local agencies and organizations to organize the local nonprofit corporation. At the same time, the Special Assistant to the Governor would request the state agencies to work cooperatively with these local groups in order to develop a local plan satisfactory to all concerned. This will automatically give priority to the approximately 39 counties in which local ARC's are now functioning.

Local ARC's are now operating in all or practically all counties in which there are services for the retarded -- in fact, formation of a local ARC is normally the first step in securing local services for the retarded. The Tennessee Association for Retarded Children and Adults is working to organize additional local ARC's with the goal of having one in each of Tennessee's 95 counties. These organizational efforts will be stepped up as local interest develops in community care centers. In this way a local ARC will be available to take the leadership in organizing a local nonprofit corporation as soon as a community is ready to work toward a community care center.

Considerable work will be necessary in organizing the local nonprofit corporations and in developing the by-laws under which they will operate. Orange Grove School may serve as a guide but it will be necessary for the state agencies to work cooperatively with the local ARC's and community leaders in developing an organizational structure and a plan of operation that will be satisfactory to all concerned. The proposed Special Assistant to the Governor can be extremely helpful in coordinating this work and making sure each local corporation is soundly organized, appropriately financed, and has a plan of services that is in keeping with the needs of the community. His assistance and that of the local university will be particularly essential in developing plans for the regional centers, expecially for the comprehensive diagnostic services to be provided for the metropolitan area and the region served.

V. RECOMMENDATIONS

To serve the needs of the retarded in the community, to educate and train the retarded for jobs in the community, and to reserve the state institutions for those who are so severely retarded that they cannot be cared for properly in the community, it is recommended:

1.) That six regional community care centers be established at Memphis, Jackson, Nashville, Chattanooga, Knoxville and Johnson City. Each center would provide comprehensive diagnostic services for the retarded in the surrounding region, would send traveling teams of specialists as consultants to the smaller centers in the region, and would provide a full array of services for the retarded. Major services, in addition to diagnosis, would include preschool classes, day-care services, sheltered workshop services, vocational training services, recreational services, long-term and short-term residence, and services for parents. Research and demonstration projects would be conducted, training would be given to staffs of the smaller centers, and special problem children would be accepted from the surrounding region. The centers would be located, insofar as practical, on the campus or in close proximity to a university and would cooperate closely with the university.

2.) That community care centers be established in the other three or more metropolitan communities, such as Oak Ridge, Kingsport and Bristol, and that each provide the major services listed above exclusive of diagnosis and services for the surrounding area.

3.) That smaller community care centers be established in the remaining approximately 25 communities having a population over 10,000. The services would vary somewhat with the population, residential facilities being omitted in all but the largest communities.

4.) That still smaller community care centers be established in the remaining 40 or 50 counties or communities located in sparsely settled rural areas. Services would vary extensively with population, but each would have SMR and EMR classes and perhaps a combination day-care, sheltered workshop, and vocational training service.

5.) That each community care center consist of a single modern building or closely associated group of buildings located on a carefully selected site and designed to house not just present services but for expansion to meet future needs.

6.) That the State assign a licensed architect to study the facilities needed to house the services outlined, to prepare typical plans and to assist each community in selecting a site and planning its community care facilities. The State would not make construction funds available to a community until the site and the design have been approved by the State architect.

7.) That the community care centers be owned if possible and administered by a local non-profit corporation organized for the purpose. Each corporation would have its own Board of Directors composed of interested local citizens and would employ a full-time Director to administer the program and facilities, except in the smallest communities where a part-time director would serve until the services of a full-time Director are warranted.

8.) That the local ARC take the leadership in calling together representatives of the local agencies and organizations to work out a plan for organizing the local non-profit corporation and that the Special Assistant to the Governor (proposed in chapter on Coordination and Implementation) work through the proposed Interagency Committee in coordinating local plans satisfactory to all concerned.

9.) That standards for each service provided be set by the appropriate State agency and enforced both through licensing regulations and through control of State and Federal funds used for construction of facilities and operation of programs.

In conclusion, the retarded have been treated as second-class citizens far too long, both for their own good and the good of society. The special services they need have been provided only to a limited extent and then only for a limited number. Most of these services have been provided by the poorly coordinated efforts of a variety of volunteer groups using abandoned school buildings and other facilities available at little or no cost. The time has come for this three percent of the population and their parents to receive services appropriate to their needs and to have these services housed in modern buildings constructed for the purpose. Only in this way can a great majority of the retarded be transformed from a liability of society to an asset.

RESIDENTIAL FACILITIES

Based on the Report of

The Problem Study Group on Residential Facilities

RESIDENTIAL FACILITIES

Tennessee's residential facilities being admittedly inadequate in quantity and quality, this chapter attempts to formulate some guidelines, ideas, and means for improving these facilities within the proposed comprehensive, state-wide program for the mentally retarded. Until recently, residential care was the only service of any significance provided in Tennessee for all retardates, regardless of the severity of the handicap. Now the whole thrust of the proposed services for the retarded is to keep them at home and to involve them in varied educational and training programs. Nevertheless, a retarded individual may require residential care for part or all of his life. It may be only for a few weeks of evaluation, for brief behavior training or while the family is vacationing; or it can be for a lifetime of care as in the cases of the severely retarded and of those without other homes. The following statement taken from "National Action to Combat Mental Retardation" is an excellent summary of the role residential facilities should play in a comprehensive program. "The challenge to State institutions is how to accelerate the change from large isolated facilities to smaller units close to the homes of the patients and to the health, education, and social resources of the community; and the challenge to both State and private residential facilities is how to replace the old concept of custodial care, wherever it still exists, with modern programs of therapy, education and research."

I. THE INSTITUTIONAL PATTERN

A relatively small but important group of retardates present problems with which many communities cannot cope because of a lack of facilities. These individuals need intensive medical and protective care in contrast to the needs of most retardates. The following are the types of facilities envisioned.

1.) Comprehensive central institutions for: diagnosis, evaluation, intensive care and services requiring a highly specialized staff, and research.

2.) Satellite facilities for those not in need of intensive care or treatment.

3.) Ancillary facilities for day care, vocational training, sheltered workshops, and residential programs.

RECOMMENDATIONS

A. The Central Institutions

It is recommended that Tennessee's present large institutions - Clover Bottom

Hospital and School at Donelson, Greene Valley Hospital and School at Greeneville, and the one under construction at Arlington (Memphis) be designated the comprehensive central institutions; and that these specialize in diagnosis, evaluation and intensive care for residents requiring services not conveniently obtainable at the community level.

B. The Satellite Institutions

A network of satellite facilities should be established to care for those not in need of intensive treatment. These facilities should be located according to population and should be near supporting services, including institutions of higher learning. Each of these centers should have a resident capacity of 250 to 500 retardates, and would care for those being referred into or out of central institutions. These satellite centers would also provide examinations as a screening device to reduce the present formidable waiting lists for admission to the central institutions. While these satellite centers will handle the overflow of patients requiring domiciliary care from the central institutions, their programs and functions should be geared primarily toward training rather than care.

The satellite facilities envisioned here correspond to the Regional and Metropolitan centers and to the larger communities of Medium Size Centers recommended by the "Community Care Centers" report.

II. GOALS OF THE INSTITUTIONS

The primary goal of a program of services for the retarded is to keep the child as close to home as possible. In pursuance of this goal, it is recommended that the satellite centers provide: (1) day care and residential services, (2) vocational training and sheltered workshop programs in appropriate facilities, and (3) consultation and supportive services to the retardates and their families.

III. PROGRAMS OF THE INSTITUTIONS

It is of utmost importance that the total program of each institution be planned prior to the design of the building. The building, equipment, and the services capable of being rendered must all reflect the comprehensive program developed to meet the needs of the retarded.

A. Central Institutions

The major proposals with respect to the central institutions are the following:

(1) The facilities should not be set apart from communities by fences or other barriers. Fences suggest to the layman that either they are not welcome or that the facility houses dangerous inmates, has something to hide or is simply shrouded in mystery. Fences are not needed but are sometimes resorted to as a substitute for proper training and supervision.

(2) The central institutions should replace the ward system of living facilities with cottage-type arrangements. Where this is not feasible, unit supervisors should be made responsible for small groups within the complex.

(3) Locked facilities should be unlocked and training and activity programs substituted for custodial and unprogrammed care.

(4) Research should be an integral part of these institutions' programs. Recent advances in medicine, treatment, and training indicate that goals for patients can be set higher and that more intensive research is warranted.

(5) A research consultant position should be established at each central institution to encourage individual participation by staff members in the research process and to promote contributions from satellite centers.

(6) Each central institution should draw on professional persons from the various disciplines dealing with physical and mental problems of children to establish a volunteer committee designed to evaluate and channel to appropriate services the multiply-handicapped children not clearly the responsibility of a single agency or institution. Such a committee could save time, effort, and money by greatly reducing duplication of community services and could be the means of opening doors that have been heretofore closed to certain multiply-handicapped children.

B. Satellite Centers

It is recommended that the satellite community-level centers provide such specific services as:

(1) Residential care during family crisis or vacations.

(2) Brief behavior training and follow-up services to insure that the behavior is maintained in the home.

(3) Intensive skill training for vocational goals.

(4) Consultation by center personnel to representatives of special education, head-start, economic opportunity and other programs.

(5) Consultation with parents on behavior training and maintenance of

such patterns by periodic check-ups at the central institution.

IV. PERSONNEL FOR RESIDENTIAL FACILITIES

Because of the basic fact that professional personnel are expensive and in short supply, the following recommendations are made in the hope of overcoming this problem as well as possible.

(1) A new category - a professional category of "training specialists" - should be established and included in the organizational tables of the satellite centers. These specialists would limit their direct services to retardates and would devote most of their energies to prescribing programs, training other more available workers to render skilled services, and consulting with community agencies, parents, and others concerned.

(2) Imaginative use should be made of part-time personnel.

(3) Full-time and part-time program consultants should be continuously employed by the Department of Mental Health to insure that all future facilities and services are well-planned. Too often in the past program decisions have been relegated to architects employed to design the facility.

(4) It should be recognized that having a degree does not necessarily qualify a person as an administrator. All disciplines should be represented in policy and program planning and implementation, and these programs must be coordinated by an administrator possessing specific competencies to insure maximum teamwork and contribution from the different departments.

(5) An Interagency policy-making and advisory board should be established since personnel must be contracted from many sources and since the institutions will be dealing with many agencies and community groups.

V. ADMINISTRATIVE PROCEDURES

The following are the major recommendations for the administration of residential facilities.

(1) Institutions should be operated under a flexible admission and release policy with an increased emphasis on out-patient services.

(2) The position of Director of Standards for Mentally Retarded Care Centers should be established in the Health or Welfare Department to set licensing

standards for all institutions providing care for retardates and to set rates which would permit these licensed institutions to maintain the required standards.

(3) Agreements should be negotiated whereby the time of personnel in the various state agencies can be bought, loaned, or exchanged to allow for maximum utilization of highly trained personnel in the mental retardation programs.

(4) Contractural agreements should be reached in the field of research and to insure future progress.

COORDINATION AND IMPLEMENTATION OF PROGRAMS

This Chapter is Based on the

Report of

The Problem Study Group on Coordination and Implementation
Of Programming for the Mentally Retarded

COORDINATION AND IMPLEMENTATION OF PROGRAMS

For the purpose of this report, coordination of programs for the mentally retarded refers to the process by which the state departments and agencies work together in harmony to avoid overlap between programs and to avoid gaps between programs for the retarded. Implementation of programs for the mentally retarded refers to the process of carrying out the recommendations made by the various committees working under the planning grant and as brought together in this report on comprehensive mental retardation planning.

Coordination of services for the retarded has been a problem not only in Tennessee and other states, but also at the national level. The retarded have been neglected for so many years that there has been little incentive for the various agencies to push existing programs for the retarded or to initiate new programs at the national, state or local level. Existing programs have been confined largely to residential care in state institutions operated by the Department of Mental Health and special education through the public school systems with financial assistance from the Department of Education. There has been little evidence of coordination between these two programs. Furthermore, the other departments of state government have done little to coordinate their work with these two departments or to develop programs of their own for the retarded. Coordination of programs at the state level becomes even more imperative as existing programs are expanded and new programs started under the impetus of the current planning studies and the increased Federal funds available to the State. It is essential that available funds be spent wisely, that there be no duplication of services by the different departments, that new programs be undertaken by departments best equipped to provide and promote these programs, and that there be a central person or group with responsibility and authority to decide which programs should receive greatest emphasis and to provide the initiative and drive necessary to obtain funds and expand services.

A federal grant of $40,000 a year for a two year period can be obtained to finance the staff and travel needed to carry out the coordination and implementation.

I. POSSIBLE ALTERNATIVES

The following alternative methods by which coordination and implementation of programs for the retarded might be secured at the state level were explored.

1.) Create a new Department of Mental Retardation or a new Department for the Handicapped and Disadvantaged.

2.) Create an Interagency Council on Mental Retardation.

3.) Create in each department a division or unit on mental retardation.

4.) Appoint a Special Assistant to the Governor on Mental Retardation or on the Mentally Retarded and Other Handicapped.

Each of these possible alternatives was explored in detail and note made of the advantages and disadvantages of each. The results of these discussions are reported briefly.

A. Department of Mental Retardation

Creation of a Department of Mental Retardation and transfer to this department of all or practically all programs for the retarded would be advantageous in that the Commissioner would be in a position to initiate and direct all or practically all state programs for the retarded. Coordination and implementation of programs would no longer be a major concern. This department would be able to tap the many sources of Federal funds, would work directly with the community care centers for the retarded proposed in this report, and would be the single point of contact in the state for individuals and local organizations interested in the retarded.

To this new department would be transferred the hospitals and schools for the retarded now operated by the Department of Mental Health, the special classes for the severely retarded and perhaps those for the educable mentally retarded now sponsored by the Division of Special Education of the Department of Education, the training centers and the rehabilitation counseling for the retarded now conducted by the Division of Vocational Rehabilitation of the Department of Education, and numerous lesser services now provided by other state departments. New services for the retarded, such as pre-school classes, day-care centers, and sheltered workshops, would automatically come under this department.

Off-setting these major advantages would be equally serious disadvantages. The very earliest that a new department could be created would be July 1, 1967, following action by the 1967 legislature. Some time would be required to organize the department, employ staff, and get a program underway. Thus, at least a year would be lost -- right at a time when progress should be greatest under the impetus of expanded Federal and local activities.

Selection of existing programs and activities to be transferred to the new department would present many difficulties. Some programs, such as the special classes for the severely retarded and the vocational training centers for the retarded, should be transferred, but many arguments could be presented both for and against transfer of the special classes for the educably retarded. In any case, it would be impractical to transfer to the new department _all_ existing services for the retarded.

As a result, all problems of coordination of services for the retarded would not be solved.

Transfer of existing programs to the new department would be resented to some degree by the other departments, and this might hamper interdepartmental efforts for many years to come. Some departments might resent creation of a new department so strongly as to take steps to prevent creation of such a department. In any case, the new department would find itself hampered in its relations with other departments. Staffing the new department might also present serious problems because of the extreme shortage of competent specialists, particularly in view of the relatively low state salary scale.

Creation of a department for the Handicapped and Disadvantaged might offer some additional advantages in that it would be able to secure broader local support and more extensive federal funds, but these advantages would probably be more than off-set by the greater disruption caused in other state departments and by the dilution of services for the retarded by the need to provide services for so many other deserving groups.

B. Interagency Council on Mental Retardation

This Council, composed of the heads of departments or agencies responsible for services for the retarded, would meet regularly to coordinate their activities for the retarded. Through these meetings, the departments would become familiar with the services being provided by all departments, would become aware of services that need to be strengthened or reduced and new services that should be started, and, hopefully, should be able to agree on who should do what to better serve the retarded.

This plan sounds good -- in theory. Practical experience has demonstrated, however, that an Interagency Council is not, by itself, a suitable instrument for coordinating or implementing services. For example, the legislation enacted in 1955 to provide special classes for the severely retarded in the public schools also provided for an interagency committee to coordinate this program with other programs for the retarded. This committee met once. Despite the fact that it was created by the Legislature, the committee never met again. It was a complete failure. Numerous similar failures were recalled by committee members in the course of committee deliberations.

Each commissioner has problems of his own that he prefers to solve in his own way without the advice of other commissioners who cannot share his responsibilities. In particular, each is responsible for using the funds available to him in a manner that will best serve the programs of his department; he cannot let others at the same level who do not share his responsibilities tell him what to do. Simply stated, administrators at the same level in any organization usually have the tacit understanding: "You keep your fingers out of my pie and I'll keep mine out of yours."

With respect to services for the retarded, it is abundantly clear that an Inter-Agency Council would not produce the essential coordination and implementation. Services for the retarded are not the major responsibility of any department of Tennessee government at the present time. Even in the Department of Mental Health, which operates the state institutions for the retarded, expenditures for the retarded are only one-fifth of total expenditures. The proportion is still less in the other departments. To expect an administrator to strengthen such a minor program at the expense of his major programs upon the recommendation of other administrators at the same level is not realistic.

C. Departmental Divisions of Mental Retardation

Under this plan each department having significant program interest in mental retardation would form a division or unit on mental retardation that would be headed by an assistant commissioner with authority and responsibility to promote programs for the retarded. It is unlikely that this plan by itself, would accomplish a great deal because of continued lack of coordination between the departments. Mental retardation would probably remain the step-child within each department. However, this plan, combined with the plan for an Interagency Council supervised by a person in higher authority, could be more productive.

D. Special Assistant to the Governor

Under this plan the special assistant would serve at the state level in much the same manner as Dr. Stafford Warren served at the Federal level. He would be appointed by the Governor and would, of necessity, need to have the Governor's backing. The Special Assistant would need to be familiar not only with the subject of mental retardation but also with the working details of state government, and in addition would need to be an astute politician. He would need an executive assistant and several clerks.

The Special Assistant would work primarily through and with an Interagency Committee composed of a high-level representative of each department or agency. This committee would need to meet frequently, perhaps every other week, with the Special Assistant as chairman.

It would also be desirable for the Governor to expand the Advisory Council on Mental Retardation that he appointed in November, 1963 to a total of perhaps 50 lay and professional leaders from all parts of the state. Members might be appointed by the Governor for staggered terms of perhaps three years. The Governor should also appoint a chairman instead of having the Council continue to elect its own chairman. The Special Assistant would serve as executive secretary. The committee would meet twice a year to hear reports on progress and problems, to offer suggestions on the programs, and to serve as a public sounding board for various proposals.

The Advisory Council would have an executive committee that would meet at least quarterly to provide the Special Assistant a group with whom he could consult more frequently. It might consist of seven members of the Advisory Council, four appointed by the Governor and three elected by the Council. The chairman of the Advisory Council would serve as chairman.

This plan has a number of distinct advantages. It could be put into operation almost at once and could be financed largely by the $40,000 a year Federal grant that can be obtained for the purpose. It would place responsibility and authority for the State's entire program for the retarded in the hands of one man who would be in a position to consult directly with the Governor when necessary and to persuade the departments to carry out the agreed-upon programs. Good coordination would be obtained through the Interagency Committee. This committee, under the leadership of the Special Assistant, would also facilitate development of new programs and assignment of each program to the department best able to carry it out successfully. The Advisory Council would serve not only as a sounding board for new ideas and programs but also would, through its broad distribution across the state, be in a position to reflect public sentiment and to secure public cooperation.

Expanding the position of Special Assistant to include other handicapped as well as the mentally retarded seems to have little merit at the present time. So much needs to be done for the retarded now and in the immediate future that the Special Assistant will have his hands full. Expanding his duties would dilute his efforts at the very time major efforts are required. It may, however, be desirable to review the situation some years hence when the new and expanded programs for the retarded are operating smoothly to see if it may then be desirable to expand the Special Assistant's duties to include other handicapped and perhaps to include the disadvantaged.

II. RECOMMENDATIONS

To better coordinate and implement at the state level the existing programs for the mentally retarded of Tennessee and more particularly the new and greatly expanded programs that are expected to result from the increased nationwide interest in the retarded, the intensive planning studies now being conducted, and the Federal funds expected to be available , the committee recommends:

1.) That the Governor appoint a Special Assistant on Mental Retardation to serve much as Dr. Stafford Warren served as Special Assistant to the President. He would have an executive assistant and clerical help.

2.) That there be created an Interagency Committee composed of a high-level representative from each department or agency with the Special Assistant serving as chairman.

3.) That the Governor expand the Advisory Council on Mental Retardation that he appointed in November, 1963, to a total of some fifty lay and professional leaders from all parts of the State. The Council would meet twice a year to hear reports on progress and problems and to offer suggestions on the programs. The Governor should appoint a chairman instead of having the Council elect its own chairman. The members should be appointed for staggered terms of perhaps three years. The Special Assistant would serve as executive secretary. An executive committee would meet at least quarterly.

4.) That immediate action be taken to secure a Federal grant of $40,000 a year for two years and that matching funds or services be provided as necessary. These funds would be used to support the special assistant and his staff and to cover travel cost of the Advisory Countil and its executive committee.

APPENDIX A

Commissioner of Mental Health	Dr. Nat T. Winston
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Assistant Director of Planning	Mr. Walter M. Mitchell

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Mr. Wylie Bowmaster, Knoxville
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The Honorable Herman Robinson, Elizabethton
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The following list comprises those members of State Agencies and the Board of Trustees of the Tennessee Department of Mental Health who were added to the Council in order to meet the requirements of the roster for the Advisory Council on Construction of Facilities for the Retarded:

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Mr. William Black, Gallatin
Mr. Vernon Johnson, Department of Education, Nashville
Mr. E. O. Reece, Division of Vocational Rehabilitation, Nashville
Mrs. Alberta Boyd, Department of Employment Security, Nashville

APPENDIX B

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Working with this committee as liason from the Committee on Finance:

Mr. Otis Hurst
Dr. W. N. Cooke

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APPENDIX C

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